

# National Haemophilia

Haemophilia Foundation Australia

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

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**15<sup>TH</sup>**

Australian & New Zealand

**HAEMOPHILIA CONFERENCE**

*Life Challenges* 

Brisbane, 8-10 October 2009 [www.haemophilia.org.au](http://www.haemophilia.org.au)

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# JENNIFER ROSS AWARDS

The HFA Council presented Awards to two well known physiotherapists in the bleeding disorders community at the Gala Dinner of the 15th Australian and New Zealand Haemophilia Conference.

Haemophilia Foundation Australia (HFA) President Gavin Finkelstein announced that Wendy Poulsen, physiotherapist at the Royal Children's Hospital in Brisbane and Brendan Egan, physiotherapist at the Royal Children's Hospital in Melbourne were the recipients of the HFA Jennifer Ross Award.

The Award is only given occasionally and is for health professionals and others working in a professional role with Haemophilia Foundations, at Haemophilia Centres or other organisations that support people with bleeding disorders. It recognises an outstanding contribution that is beyond the normal expectation of the person's professional role or special service to people with bleeding disorders and their families.

Brendan Egan has worked for several years with patients and families with bleeding disorders in Victoria. He has contributed to the development of education resources for families and presented at conferences and workshop in Australia and overseas. His publication, *Boys will be Boys: A*

*guide to sports participation for people with haemophilia and other bleeding disorders* is used widely. Brendan has assisted the streamlining of the transition process of children from RCH to the adult setting at The Alfred in Melbourne. Until recently Brendan was one of the Co Chairs of the Australian and New Zealand Physiotherapy Haemophilia Group.

Wendy Poulsen has also participated actively to improve the health and quality of life of her young patients and support their families, and advocates for health and fitness to be included as part of the overall care and management for children with haemophilia. She has actively supported Haemophilia Foundation Queensland and HFA in the development of education resources



Wendy Poulsen with her Jennifer Ross Award

and programs and she had a lead role in the establishment and strengthening of the Australian and New Zealand Physiotherapy Haemophilia Group.

Wendy received her Award at the Gala Dinner, and Brendan's Award will be presented to him at a later date. **H**

It recognises an outstanding contribution that is beyond the normal expectation of the person's professional role or special service to people with bleeding disorders and their families.

# HFA'S BID FOR INTERNATIONAL CONGRESS OF THE WORLD FEDERATION OF HEMOPHILIA IN 2014

*Sharon Caris*

International Congresses of WFH are the peak education meetings for the worldwide bleeding disorders community, and they are also one of the most important ways for WFH to generate funds for programs and services around the world.

The WFH Congress has never been held in Australia. After a local selection process to seek a suitable venue for Congress which already attracts nearly 4500 delegates, the HFA Board decided to propose Melbourne for the Congress in 2014. If this bid is successful it would follow the Congresses to be held in Buenos

Aires, Argentina in July 2010 and Paris, France in 2012.

HFA has submitted a detailed bid which we believe would offer an affordable, accessible, inclusive and profitable Congress for WFH taking into account the national, regional and international developments on the horizon. With the support of member Foundations, the scientific and clinical professionals around Australia, we have offered a proposal which we believe will offer a successful Congress in Australia.

HFA was delighted to hear in September that it had reached the

next stage of the process and that WFH would conduct a site inspection in November. There is strong competition from Malaysia, Mexico and USA, which are the three other National Member Organizations also being considered for Congress in 2014. The WFH Executive Committee will decide in early 2010 which two countries will be voted on by National Member Organisations at the General Assembly of WFH in Argentina in July 2010. **H**



# HFA – CELEBRATING 30 YEARS

Suzanne O'Callaghan

In 2009 Haemophilia Foundation Australia celebrated its 30 year anniversary. It seemed appropriate to mark the anniversary at the Haemophilia Conference dinner with a short video documenting HFA's remarkable journey since it was established in 1979.

The story of HFA's development was told through interviews with current and former members of the HFA Council and health professionals with longstanding involvement in HFA. This was illustrated with photos and samples of newsletters and resources from HFA's collection – a trip down memory lane for many people at the dinner and a revelation for those who have joined HFA more recently.

The former HFA Executive Director, Jenny Ross, remembered the extraordinary time at the start of the AIDS epidemic in 1984 where HFA was suddenly transformed from a small national organisation to an active and respected member of national and international teams struggling to understand and deal with the issues – a time of great upheaval and sadness. The lessons HFA learned during this period served it well and were built on through the advocacy campaigns of the time and those that followed – the campaign for HIV financial assistance, campaigns to make prophylaxis available to young people and recombinant treatment accessible to all Australians with bleeding disorders, the HFA representations to the Senate Inquiry into Hepatitis C and the Blood Supply.

Other happier times were also recalled: the feeling of connection at Haemophilia Conferences; moments when HFA Council had fun and relaxed; developing the diverse range of high quality HFA resources on a shoestring; HFA events and programs such as Red Run Classic, the Youth Leadership and Mentoring Program and its support for state and territory camps and groups. Health professionals talked about the impact of HFA's support for the haemophilia health professional groups – that it gave a reason to focus nationally on haemophilia care and build an expertise that is recognised internationally.

Thanks to all those who participated in the video – and to all those who have contributed to HFA over the years and have made it the organisation it is now. **H**

First meeting of Australian Federation of Haemophilia Societies, 1979 – L-R Ted Troedson, Neville Acklom, Alison Bellamy, Bevlee Beveridge, Jenny Ross, (insert) Alan Ewart.



# HFA COUNCIL MEETING AND AGM

*Sharon Caris*

At the close of the 15th Australian and New Zealand Haemophilia Conference on 10 October, Haemophilia Foundation Australia (HFA) Council Delegates stayed in Brisbane for the Council Meeting and Annual General Meeting (AGM) on the Sunday and Monday. There was a lot to cover at the meeting including hearing reports from State/Territory foundations, outcomes of HFA projects throughout the previous year and making plans for the next years.

At the AGM President Gavin Finkelstein expressed appreciation to Peter Mathews who had recently stepped down from the HFA Board and as one of the Delegates for HFNSW. Peter has been a Vice President and Executive Board member for several years and has made an outstanding contribution. Peter continues to work closely with HFA in his role as Executive Officer at HFNSW.

At the AGM elections Gavin Finkelstein was re-elected as President, Peter Fogarty was elected as Vice President and Jonathan Spencer was elected as Treasurer. Paul Bonner and Ann Roberts were also elected to the Executive Board. H

## 2009-2010 Council

Gavin Finkelstein, HFWA	President
Peter Fogarty, HFQ	Vice President
Jonathan Spencer, HFT	Treasurer
Paul Bonner, HFSA	Executive member
Ann Roberts, HFV	Executive member
Lorraine Saunders,	HFACT
Bill Atkinson,	HFNSW
David Taylor,	HFNSW
David Stephenson,	HFQ
Tony Kennewell,	HFSA
Chantel Roberts,	HFV
David Bell,	HFWA



Top (l-r) David Bell, Peter Fogarty, Gavin Finkelstein, Paul Bonner, Tony Kennewell, Bill Atkinson

Bottom (l-r) Lorraine Saunders, Ann Roberts, Chantel Roberts, Jonathon Spencer, David Taylor



## AIDS AWARENESS WEEK

AIDS Awareness Week was held from 23-30 November in 2009, with World AIDS Day celebrated on Tuesday 1 December.


The theme for this year was: "Take action. No discrimination." and focused on the need to understand the needs of people with HIV and support them to live a life free of discrimination. This reflects the feedback from Australians affected by HIV, including some members of the bleeding disorders community, that in 2009 stigma and discrimination continue to be major issues that impact on their everyday lives.

World AIDS Day gives an opportunity to pause and acknowledge the people with bleeding disorders and their partners and families around the world who were affected by the HIV/AIDS epidemic in the mid-1980s when HIV was found in some blood clotting treatment products. In the early 1990s they also found their blood products had been affected by hepatitis C. Since then haemophilia treatment product safety has improved greatly and the risk of new infections from using human blood products is now thought to be extremely low. In 1985 HIV testing and inactivation was introduced for Australian blood products. Children and previously untreated adults with haemophilia have been treated since the mid 1990s in Australia with recombinant treatment products which are genetically engineered and contain little or no human material. In

2004 Australian governments agreed to fund sufficient supplies of these recombinant clotting factors for people with haemophilia of all ages.

Haemophilia Foundation Australia held a Remembrance Service during the 15th Australian and New Zealand Haemophilia Conference in October to remember those in the bleeding disorders community who have died.

Throughout the world many people wear the HIV/AIDS Red Ribbon on World AIDS Day to declare support for HIV positive people and those who are affected by HIV/AIDS. It is a symbol to the memory of those who have died and support for those who live with HIV. In 2009 our challenge is to put the symbol into action by finding ways we can strengthen our support to affected members and work towards a community free of discrimination.

For more information about World AIDS Day, go to [www.worldaidsday.org.au](http://www.worldaidsday.org.au) or contact your local HIV organisation or HFA. 

...focused on the need to understand the needs of people with HIV and support them to live a life free of discrimination.

# “GRASS ROOTS TO NATIONAL ACTION”: 2009 NATIONAL HEPATITIS HEALTH PROMOTION CONFERENCE

*Suzanne O'Callaghan*

It's often said that history repeats itself and this is something that came to mind when I attended the National Hepatitis Health Promotion Conference in Hobart on October 28 and 29 2009. With the theme of “*Grass roots to national action*”, the conference provided a forum for representatives from community organisations, health care organisations, universities and government to focus on health promotion strategies and issues for hepatitis B and C.

In the first plenary we heard about the widespread complacency in Australia towards preventing hepatitis C transmission, particularly among those at high risk of infection. A suggestion by James Ward, who is the Senior Lecturer in Aboriginal and Torres Strait Islander Health at the National Centre in HIV Epidemiology and Clinical Research, that a strategy like the Grim Reaper HIV campaign in the late 1980s was needed to gain

the community's attention met with mixed responses. Only the week before this conference HFA had heard feedback about the ongoing negative impact of the Grim Reaper campaign from HIV positive bleeding disorders community members. HFA is unlikely to support a health promotion strategy like this, given those negative experiences. It is interesting that, 22 years after the first Grim Reaper campaign, the concept was again raised for debate. It certainly created a lot of discussion at the Conference, with others also concerned that it could create more stigma for the community with hepatitis C.

The conference provides a useful opportunity for workers in the field to explore innovative strategies for health promotion. The session on People Living With Hepatitis was particularly interesting, with presentations on disclosure at work, the program for GPs to prescribe

hepatitis C treatment and a program to provide practical social services and support to people during treatment, eg housecleaning, gardening, shopping, visits – all of which were key issues in the HFA hepatitis C needs assessment. I also presented on HFA's Wellbeing Weekend pilot. Other highlights were the sessions on using Facebook and Twitter for health promotion and the very creative youth-based projects.

HFA participates in the Conference Project Reference Group (PRG), which is managed and convened by Hepatitis Australia to plan the Conference and its program. As HFA's representative on the PRG, I attended the Conference and found it a stimulating and valuable experience. Thanks to Hepatitis Australia for their invitation to participate and to HFA for supporting me to attend. **H**



A large '15' with 'TH' in a smaller font to its upper right, all enclosed within a circular graphic element.

# Australian & New Zealand

## HAEMOPHILIA CONFERENCE

*Life Challenges* The HFA logo consists of a stylized 'H' followed by a dot, all enclosed in a circular shape.

**Brisbane, 8-10 October 2009** [www.haemophilia.org.au](http://www.haemophilia.org.au)

The 15th Australian & New Zealand Haemophilia Conference was very successful, with more than 230 delegates from Australia and New Zealand and a program that included presentations on the state of the art in the treatment and care of bleeding disorders by Australian and International speakers.

The annual meetings of the Australian Haemophilia Nurses' Group, Australia and New Zealand Physiotherapy Haemophilia Group, Australian Haemophilia Counsellors' and Social Workers' Group, Australian Haemophilia Centre Directors' Organisation were held on 8 October. It is exciting that for the first time a group of dentists with a special interest in the treatment of people with bleeding disorders met and the Australian Bleeding Disorders Registry Data Managers also met for the first time.

You can refresh your memory, or if you missed the Conference, catch up with the latest research and discussions with the Conference abstracts and presentations, which are now available on the HFA web site. Visit [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) and follow the links to Presentations.

HFA Council Delegates have prepared the following conference reports for your interest.

### Friday 9 October 2009

#### Plenary 1

**Chair: Maureen Spilsbury**

**Assessing the impact of chronic disorders on Adolescents**

~ Dr Michael Carr-Gregg

*Chantel Roberts (VIC). Chantel is a member of the Haemophilia Foundation Victoria (HFV) Committee and one of the HFV delegates to the HFA Council*

In the opening plenary session of the Conference, well known adolescent psychologist Dr Michael Carr-Gregg explained that the period of adolescence is characterized by four main changes – physical, psychological, social and sexual. And, there are four ways to assess a young person's development – their attachment to school, their attachment to outside tasks, their attachment to

peers/relationships, and detachment from carers.

Adolescents with a chronic illness have a much higher risk of suffering depression/anxiety/suicidal behaviour.

Dr Michael Carr-Gregg defined adolescence as being young people aged 10 – 24. He also mentioned that the adolescent brain is always developing. As a young person with a chronic illness is moving from the childhood to adolescent phase, it is likely that treatment compliance will decline, which poses serious health risks.

Later in the presentation, Dr Michael Carr-Gregg went on to talk about the psychology of positive emotions. He proposed that the meaning of life is to be happy. He mentioned that extremely happy people are not more religious, or not physically fitter. Extremely happy people are highly social and in a romantic relationship.

Dr Carr Gregg's presentation was finished with 8 secrets of happiness.

Count your blessings: write 3-4 things weekly that you're grateful for, no negatives

- Practice acts of kindness: the more nice things you do for other people, the happier you will be
- Savour life's joys: pay attention to momentary wonders or joys
- Thank a mentor: if there is someone who has helped you through a rough patch in your life, thank them
- Learn to forgive: learning to forgive enables you to move on
- Invest time and energy in family and friends: find a balance
- Take care of your body: sleep, exercise, stretch and laugh!
- Develop strategies to cope with stress: positive self talk, religious beliefs

Lorraine Saunders (ACT) Lorraine is a member of the Haemophilia Foundation ACT (HFACT) and HFACT delegate to Haemophilia Foundation Australia Council

What a fantastic way to start the conference! Dr Carr-Gregg was an entertaining, humorous and informative speaker who had his audience engaged from beginning to end with no end of laughing which only assisted us to absorb the serious side of his message. We were given a wonderful overview of the modern teenager, how they develop, how their brain works (or doesn't!). His overheads included cartoons and videos and a representation of Gen Y which is well worth the visit to the 'presentations' page on the HFA website to view. He really brought home the pressure and stresses placed on adolescents who also have a chronic illness. The risk of suicide is increased by a factor of 5 for these young adults. He also stressed the importance of not neglecting the siblings and the role they play. I think a few of us had an 'Aha' moment at this point.

Dr Carr-Gregg explained the importance of understanding the balance of psychological risk and protective factors. He listed and explained those basic factors and how they influence and play a role in the lives of teenagers. He stressed the importance of family and of asking the right questions and continuing to ask questions of our children. What are their inherent skills? How do they want to use them? Find out who, and how they are. Identify and look for the signs of depression and get help.

I really appreciated the optimism in his talk and felt that I had been given some real tools for action. Not just at crucial or critical times – every day is important. He recommended a number of websites to visit and practical tools for dealing with the issues of having an adolescent child with haemophilia.

[www.moodgym.anu.edu.au](http://www.moodgym.anu.edu.au)

[www.reachoutcentral.com.au](http://www.reachoutcentral.com.au)

He highlighted the need for positive reinforcement and teaching optimistic thinking and in the final part of his presentation Dr Carr-Gregg described the 8 secrets of happiness. These have been outlined

by Chantal on the previous page.

Dr Carr-Gregg came with a long list of credentials, not least of which is being the Agony Uncle for *Girlfriend* magazine. Among other things he has written 5 books, been the subject of *This is Your Life* and is a co-founder of Canteen. I certainly left the session feeling inspired and ready to cope with anything. He definitely started our conference off with a buzz.

### Friday 9 October 2009

**Concurrent 3**  
**von Willebrand Disorder**  
**Chair: Dr James Daly**

**AHCDO Guidelines ~ Dr James Daly**

**Pathology and treatment**  
**~ Dr Jeremy Robertson**

**Living with vWD**

**~ Lorraine Porter-Bishop**

**~ Lauren Winders**

*David Bell (WA) David Bell is President of the Haemophilia Foundation Western Australia (HFWA) and HFWA delegate to Haemophilia Foundation Australia Council*

The session on living with von Willebrand disorder (vWD) gave me a better understanding about the types of vWD, and I learnt a great deal from the presentations. Hearing the experiences of people living with von Willebrand disorder and the personal stories of how von Willebrand disorder has impacted on their lives was valuable.

I was surprised to learn about a young boy who has type 3 von Willebrand disorder which presents similarly to severe haemophilia and he requires prophylaxis to prevent joint bleeds. Unfortunately this boy developed a target joint because he was not diagnosed properly as a young child and he later required surgery to help retain function in his ankle.

I was also somewhat confronted by the difficulties experienced by women with von Willebrand disorder who experience menorrhagia and other problems. I now have a better understanding and compassion for women with von Willebrand disorder and carriers of the haemophilia gene and the impact these conditions can have on their lives.

I was interested to learn more about the treatment for von Willebrand disorder – plasma derived factor and DDAVP and also tranexamic acid which can be effective in nose or mouth bleeds as it stops the body's natural breakdown of a clot. There is also future potential for the development of a recombinant product for the treatment of von Willebrand disorder. This is not yet available, but would reduce the risk of blood borne viruses and agents possible through plasma derived blood products.

Just as with haemophilia it is important that men and women with von Willebrand disorder are managed by bleeding disorders specialists and that they develop a good relationship with a haemophilia treatment centre to ensure good care and management of their condition.

My view about the conference program:

I thought the conference theme of Life's Challenges was spot on. The conference program was great and it was very informative! I found that most of the medical presentations could also be understood by the non medical people in the audience and the information was easy to absorb. However, I felt the sessions at the conference which really stood out were those that included the personal experiences of people living with a bleeding disorder or presentations by their families about the impact of the bleeding disorder on their family.

### Friday 9 October 2009

**Concurrent 3**  
**Haemophilia across the continuum**  
**Chair: Penny McCarthy**

**Haemophilia-talking 'bout your generation ~ Penny McCarthy**

**Maintaining health and independence, living with arthritis**  
**~ Jann Anderssen**

**Haemophilia and the added health benefits from general practice care**  
**~ A/Prof Jane Smith**

**Health issues for an ageing haemophilia population**  
**~ Dr Huyen Tran**

Penny McCarthy described the history and challenges for people

with bleeding disorders. She talked about how treatment has progressed, as well as some of the new challenges with increasing longevity. This included such things as the health complications of ageing, requirements for more support and equipment around the home, arthritis and mobility issues and the need for joint replacement surgery. It is important to have a plan for positive ageing so that you can be healthy and happy, independent and safe to remain in your home and be a part of your community. To achieve these goals we need to be able to access information and services and affectively advocate for ourselves.

Jann Anderssen continued the theme of maintaining health and independence and the role of self management in living with arthritis. She described how arthritis can impact on all aspects of life - physical, emotional, relationships, lifestyle, employment, financial, social.

Jann described the different clinical approaches to illness, chronic disease management and treatment generally. She described a clinical/curative model which is ideal for diseases that can be cured but does not take into account the social, psychological and economical impact of chronic conditions. The public health/preventative model is ideal for diseases which can be prevented. However the self management model is ideal for long term or chronic conditions.

Self management relates to knowing about the condition, monitoring and managing the signs and symptoms, engaging in activities to promote health, adhering to treatment regimes, managing the day to day impact of the chronic condition and dealing with the negative aspects and emotions that can arise.

Good self management is affected by a range of factors including:

- Motivation
- Knowledge
- Symptom management
- Co-morbidities
- Health beliefs
- Self advocacy
- Social context

- Language/literacy
- Education
- Employment
- Resources/environment
- Health Professionals
- Health System

The message that I took away from this presentation is that the self management model may not seem to be the easiest approach to dealing with a chronic condition especially when it feels like it is all getting too much, but it is the model which empowers the individual to take control and is most likely to have the best outcome.

The importance of having a good relationship with general practitioner for overall health care was stressed by Jane Smith. She went through the range of things that a GP can treat and help with, including:

- Acute & chronic care
- Emergencies
- Check Ups & Prevention
- Prescriptions
- Tests
- Certificates
- Referrals
- Immunisations
- Infections
- Asthma
- Skin conditions
- Anxiety, depression, & sleep issues
- Gastroenteritis
- Urinary and other infections
- Sprains & fractures
- Contraception, pregnancy, & STIs

Of course, a bleeding disorder might have a bearing on some of these things and a coordinated approach is necessary and specialist consultation may be necessary. Having a good GP is important, yet many people in the bleeding disorders community do not have a GP. There is nothing wrong with shopping around until you find one who you feel comfortable with. Sometimes it can be hard to see the same GP all the time, and I know from personal experience how frustrating it can be to have to go through your

medical history every time you see a new doctor, but if you have the opportunity to build a relationship with the same doctor it can be very helpful.

Finally Dr Huyen Tran spoke about the health Issues for an ageing haemophilia population.

He described a range of potential medical conditions for ageing patients with bleeding disorders including:

- chronic hepatitis
- HIV infection
- haemophilic arthropathy
- inhibitor development
- pain management
- orthopaedic surgery
- rehabilitation and physical therapy
- balance dysfunctions & risk of falls
- osteoporosis

These are all related to having a bleeding disorder, but other issues that the ageing bleeding disorders community may have to face are those that the rest of the general community need to face including such things as

- cardio-vascular disease
- cancer
- hypertension
- diabetes
- obesity
- kidney problems
- cataracts

All these things can add up and affect one's psychosocial health, through the decline in health, altered family dynamics, loss of employment and early retirement, quality of life and sexual health which can be affected by pain, haemophilic arthropathy, HCV/HIV infection, and co-morbidities such as hypertension, diabetes or kidney disease.

A positive aspect of ageing though, is to be able to look back over one's experiences and realise how learning to live with a lifelong bleeding disorder helps people to be resilient and resourceful so that we can live independently and access support and care when it is necessary.

## Friday 9 October 2009

### Plenary 2

#### Good joints for a better lift

Chair: Wendy Poulson

**The benefits of physiotherapy-exercise and fitness, maintaining healthy joints, optimising prophylaxis ~ Kathy Mulder**

**Understanding rheumatology - inflammatory processes, MRI's and radiosynovectomy ~ Dr David Kandiah**

**Orthopaedic problems and solutions ~ Dr Brett Halliday**

*Jonathan Spencer (TAS) Jonathan Spencer is President of the Haemophilia Foundation Tasmania (HFT) and HFT delegate to Haemophilia Foundation Australia Council*

In environments where there are adequate supplies of clotting factor and treatment with prophylaxis the internationally renowned Canadian physiotherapist Kathy Mulder pointed out the three myths which need to be dispelled: that treatment simply means factor replacement; that a mild bleeding disorder does not lead to joint disease; and that prophylaxis will eradicate joint disease.

Ms Mulder persuasively argued the importance of educating parents and patients to treat and prevent bleeds. In a comprehensive care model, physiotherapy sits between the medical (haematology, nursing) and chronic issues (psychosocial, orthopaedic) that face people with a bleeding disorder and is uniquely placed to provide insight and assistance to maintaining and protecting healthy joints.

Ms Mulder identified five joint-related challenges where factor replacement is readily available to people with a bleeding disorder:

1. Primary prophylaxis has the capacity to turn severe haemophilia into mild haemophilia and allow a normal lifestyle. However, studies have shown that children on prophylaxis still have joint damage and those with a mild condition still have joint damage. A significant factor is the 8-12 hour half-life of FVIII (FIX 18-24 hours) meaning that a 40%

factor level can drop to 5% in 36 hours. Accordingly, timing is everything. In practice, Ms Mulder recommends morning prophylaxis infusions rather than bedtime treatments and participation in sports on prophylaxis days.

2. Home treatment decisions rest with the family or patient alone. Infusion occurs, (hopefully) as soon as a bleed is detected. But what about ice, rest for the injured joint? Blood in a joint affects the joint (synovium and cartilage) for up to two weeks after a bleed and joint damage can occur particularly if a bleed occurs again in that period more, if weight-bearing continues and even more again if the joint cartilage is young. It is crucial that a cycle of damage to problem joints does not arise.

3. Sport and activity is good. However, appropriate selection is an issue. With on-demand treatment and prophylaxis, people with a bleeding disorder in the developed world are participating in riskier sports. The activity should match the person. physiotherapists can help in selecting the right sport and suggest solutions for possible mismatches and protective action.

4. Weight issues are not just important for people with a bleeding disorder - 60% of the adult population (25% of children) is overweight. Osteoarthritis is four times more common in the general population who are above normal body weight. Joint damage is further exacerbated if the joint is already damaged. Maintain a healthy body weight to protect your joints.

5. Use factor wisely. Maintain logs for bleeding patterns to recognise and intervene on bleeds early. Attend annual assessments to review treatment patterns and your current condition. Also, be aware, it may not be a bleed. We must treat bleeds cautiously; but remember, arthritic pain does not respond to factor.

Dr David Kandiah, rheumatologist and expert on joint disease, supported the findings of Kathy Mulder in his presentation and warned that a study has shown that delaying prophylactic treatment can result in a definite deterioration of a joint for every year after the first joint bleed. Further, another study has

revealed that more than one-half of the MRI findings were not present on plain radiographs (x-rays) suggesting that some bleeds go undetected, possibly leading to further joint degradation.

Also, Dr Kandiah reminds the audience that there are around 15% of persons with a bleeding disorder that have high levels of FVIII inhibitors. For these patients, non-surgical methods such as the conventional R.I.C.E (rest, ice, compress, elevate) and restorative physical therapies for undamaged joints and possible aspiration of a joint to improve range of movement and relieve pain are particularly important.

Brett Halliday, orthopaedic surgeon, shared his distant vision with the conference where there will be no need for orthopaedic surgeons for haemophilia conditions. Admittedly, this is a fair way off; but, the need for surgery for people with a bleeding disorder has decreased slowly over time.

Today, 80% of orthopaedic issues for people with bleeding disorders arise from ankle, knees and elbows. Chronic issues such as synovitis, cartilage damage and arthritis commonly arise. Particular problems may arise for children with growing bones and it is very important to keep joints in good condition as management become more difficult once arthritis occurs.

For people with a bleeding disorder, joint replacement is common final solution for a problem joint. Knees most commonly replaced. Shoulder and elbow replacements are more difficult and are often a last resort. Ankles are most commonly fused. Whilst the range of movement outcomes (around 60°) may be less than average, patient satisfaction remains high primarily due to significant pain relief arising from the replacement.

However, before a joint is replaced, there are other options. Surgical procedures for problem joints include: removal of the joint membrane to reduce the risks of further bleeds (synovectomy); removal of joint material (debridement); re-alignment (osteotomy) and fusion (arthrodesis) of joints, joint replacement and revision (arthroplasty).

Synovectomy may be undertaken by open surgery, arthroscopic or radiosynovectomy depending on the joint involved to reduce bleeds and pain and preserve the joint. Joint debridement has best results in a relatively preserved joint, particularly ankles and elbows.

If a surgical solution to a problem joint is selected, procedures may be combined to extend use of factor and reduce the risk of inhibitor development and shorten hospital stays.

So, where does this leave us? To me, clearly prophylaxis and on-demand treatment is not a cure for a bleeding disorder. A person with a bleeding disorder will still be prone to joint problems in the future. The extent of the problems will depend on how the patient cares for their body. Put simply, we still need to take care of our joints for a better life.

### **Saturday 10 October 2009**

#### **PLENARY 3 - The importance of Comprehensive Care for Patients, Families, Health Professionals and the Health Care System - meeting the challenges**

**Chair: Kathy Mulder**

**A young family's perspective of the comprehensive care model**  
~ Helen Fogarty

**A perspective of an adult with haemophilia - Mike O'Reilly**

**Using evidence and experience - the benefits of benchmarking**  
~ Dr Chris Barnes

**History of comprehensive care and current best practice**  
~ Dr John Rowell

**Physiotherapy - an overview - Debbie Thompson**

**Nurse - an overview**  
~ Janine Furmedge

**Social Worker - an overview - Maureen Spilsbury**

The Conference Plenary on the importance of comprehensive care is reported on by Suzanne O'Callaghan who is Policy Officer, Haemophilia Foundation Australia

What is the importance of comprehensive care to people with bleeding disorders and their families? This multidisciplinary

approach to haemophilia care is co-ordinated through Haemophilia Centres or Services and gives children and adults with bleeding disorders access to a range of care services appropriate to their life stage and health issues, including a core team of specialist haematologists, haemophilia nurses, social workers, and physiotherapists, and other specialist health professionals involved according to need.

As an adult now looking back to his childhood in the 1950s, Mike O'Reilly explored the changes that have occurred in haemophilia care and the difference it has made to his health to have comprehensive care available. He spoke of his early care – largely at home from his parents or long lonely hospital visits in reaction to bleeding episodes or trauma. Treatment was uncoordinated between hospitals and health care practitioners and expertise was limited to a few dedicated medical staff. Lack of effective treatment and slow access to treatment products meant that most of his generation experienced severe damage to their joints by their early teens.

As an older adult he now appreciates the benefits of co-ordinated and appropriate specialist care. Treatment is now proactive and aimed at preventing as well as managing health issues. Prophylactic treatment and physiotherapy tailored to bleeding disorders helps him to protect and improve his joints and muscle performance, heal more rapidly, recover to a higher state of fitness, have less call on medical services and hospital care, return to work more quickly and enjoy an improved quality of life. As he grows older, he sees the positive impact of a holistic approach which includes orthopaedics, rheumatology and in the future, cardiovascular, diabetes and dental health care in the specialised haemophilia team: information about his health is shared between his team and their multidisciplinary expertise ensures they are aware of his special needs and can care for him appropriately – and that he doesn't suffer the consequences of lack of knowledge, eg unnecessary bleeds resulting from health care procedures.

As a young mother who carries the haemophilia gene, Helen Fogarty presented a young family's perspective. Being able to rely on the multidisciplinary expertise of their Haemophilia Centre team has helped her young family to take the ups and downs of haemophilia as part of their regular healthy lives. She described the benefits in the range and quality of services, not having to re-teach health professionals, easy access to care and the emotional security of knowing that things won't fall between the cracks. With the help of genetic testing and counselling, obstetric advice, neonatal testing and support, managing port insertions for treatment and ankle bleeds, dental care, occupational therapy and travel advice and referrals, the Fogarty family have been able to play and have fun, enjoy life and maintain their health and see the world.

Bringing these services together effectively takes considerable work across several areas. Some of the health professionals who make up the Haemophilia Centre team explained how comprehensive care works from their perspective. Janine Furmedge explained the role of the haemophilia nurse – to work as a partner with the patient and their family; to be a primary point of contact between the patient and other services; providing education to patients, their families, sometimes their community, to other health professionals; helping patients to be in control of their health; planning surgery; developing and maintaining systems to optimise care; managing clotting factor treatment; helping patients to prepare for travel; reporting, researching; representing on haemophilia issues; and networking with other haemophilia health professionals.

Maureen Spilsbury described the sometimes complex role a haemophilia social worker or counsellor plays liaising between the psychosocial needs of the community and the way hospitals are set up to work. Most Centres have a designated social worker, psychologist or counsellor role. More than half regularly attend Haemophilia clinics, provide group education sessions to community

members and regularly communicate or are involved with local Haemophilia Foundations. Most undertake home visits and some operate outreach clinic services. For clients, issues can range from finances, relationships, genetic issues, family violence, death, dying and grief, and transition to health-specific problems such as hepatitis C, HIV and von Willebrand disorder. The social worker or counsellor may help with issues such as sex and sexuality, body image, relaxation strategies, reintegration into the community and adjustment to their condition – and will refer and consult with other relevant health professionals or services or community agencies such as Haemophilia Foundations on their behalf.

From the physiotherapist's perspective, their unique knowledge of how the body works and exercise can add enormously to the treatment of a patient's active bleeds and improving joints and muscles on a long term basis. Debbie Thompson described how the haemophilia physiotherapist can be involved in clinical assessment, accurate diagnosis, treatment of acute bleeds, long term monitoring of joint health, preventing bleeds, education and pre and post surgical rehabilitation. In spite of the integral role a haemophilia physiotherapist plays in the health of a person with a bleeding disorder, most haemophilia physiotherapists in Australia struggle with the lack of dedicated haemophilia time structured into their role. This also impacts on their ability to contribute to other health professionals' knowledge.

Where is comprehensive care moving to in the future? Dr John Rowell discussed the development of comprehensive care in the USA in the 1960s and 1970s – how comprehensive care has enabled patients to be involved in self-management, and how it can 'detect and minimise problems as well as... maximise benefits and long term gains.' At a medical level, comprehensive care includes specialist laboratory services as well.

While people can now have treatment home delivered and manage much of their treatment

themselves, the Haemophilia Centre's role is still integral in providing education, including self-infusion techniques, overseeing health reviews regularly and addressing the social and emotional issues of living with a bleeding disorder. Haemophilia Centres work with government on providing treatment products through the national system (which includes the Australian Bleeding Disorders Registry), advocate for treatments that provide a good quality of life, deal with complications such as inhibitors and managing the health care issues of ageing, liaise to provide rural and regional care and provide support for Haemophilia Foundations.

What about new treatments in the pipeline, such as gene therapy? The Haemophilia Centre's role will be to support the research, to assist with testing whether the treatment works through clinical trials and co-ordinate the implementation of the new treatments if they are successful. How is comprehensive care best organised? The Australian Haemophilia Centre Directors' Organisation is currently auditing Haemophilia Centres around Australia to understand what works well and where the gaps are and will present the findings to the Department of Health and Ageing.

## **Saturday 10 October 2009**

**Concurrent 1**  
**Understanding genetics and reproductive choices**  
**Chair: Dr John Rowell**

**An overview of genetics**  
~ Dr John Rowell

**How genetic counselling can help**  
~ Katherine Rose

**Preimplantation genetic diagnosis and assisted reproductive technology in haemophilia**  
~ Dr Penelope Foster

**A carrier's journey ~ Jane Devlin**

*Lorraine Saunders (ACT) Lorraine Saunders is a member of the Haemophilia Foundation ACT (HFACT) and HFACT delegate to Haemophilia Foundation Australia Council*

The issue of genetics and genetic counseling was of great interest to

me at this conference. I have a son with severe haemophilia A, who developed an inhibitor at the age of 3. Fortunately for us he has since been tolerised. He is now 23 years old and has an older sister aged 26. We have tiptoed around the idea of genetic counseling for many years but the fact is we will probably have to face the question a little more seriously in the near future. The range of speakers on this topic provided a great mix of technical, medical, administrative and personal views. It began with a refresher course on genetics by Dr John Rowell from Royal Brisbane and Women's Hospital in Queensland who explained the DNA code and also provided a brief and interesting history lesson.

Katherine Rose from Genetic Health Services Victoria spoke about the counseling process involved when families with a history of haemophilia are thinking of starting a family. Although I had given some thought to how and when our family might approach this, I hadn't any idea of the range of issues, questions or options which we might be considering. It was interesting to hear of the advances made in genetic testing, how those tests are undertaken and how to go about getting started on the process. Not all mutations are currently able to be detected and occasionally a good result can be incorrect. It can take many months to identify the specific mutation, but once this process has been undertaken, the testing of family members can be relatively quick – up to 4 weeks. The mutations are able to be identified in 98% of cases. Katherine has dealt with many families who have, or are considering genetic counselling and she referred to the many stories and circumstances which lead to the different decisions the families made.

Dr Penelope Foster from the Royal Women's Hospital in Victoria talked about in vitro fertilization (IVF) and pre-implantation genetic diagnosis. She discussed the costs of testing and the need to convince government of the benefits of testing for mutations. It's not always easy for others to see the long term benefits for society as well as for us as individuals. She included the

option of fertility treatment for the female partners of men with HIV infection.

The final presentation was by Jane Devlin who gave a sensitive and moving account of her personal journey. She shared with us how she came to, and moved through, the counseling process and all the thought processes leading to her decisions on whether or not to be tested. Her agony over not wanting to deny the life of her brother by choosing to avoid the possibility of passing on the haemophilia gene. She affirmed the strength and love of her mother for her and her brother but acknowledged the great privacy surrounding their personal stories in dealing with haemophilia over the years. There were many years of delay and deliberation before Jane finally made the decision to have the genetic counseling and I am grateful that she shared her story with us at the conference. Her wisdom and her strength were an inspiration to me.

### **Saturday 10 October 2009**

#### **Concurrent 3**

#### **Frere Papers**

**Chair: Beryl Zeissink**

**The HFNZ community needs assessment: preliminary findings, preliminary findings**  
~ Chantal Lauzon

**A retrospective audit of yttrium synovectomies at The Alfred**  
~ Dr Anne Powell

**The psoas muscle and sexual health**  
~ Matthew Stewart

**30 years' experience of joint replacements in patients with bleeding disorders in SA**  
~ Dr Lay Tay

**Outcomes after joint arthroplasty or arthrodesis at an Australian Haemophilia Centre**  
~ Dr Kemble Wang

*Jonathan Spencer (TAS)*  
*Jonathan Spencer is President of the Haemophilia Foundation Tasmania (HFT) and HFT delegate to Haemophilia Foundation Australia Council*

#### **The HFNZ Needs Assessment**

Chantal Lauzon, National

Information Coordinator (HFNZ), presented the preliminary findings from the recent 2009 member survey undertaken to hear and assess the current needs of HFNZ members. A final report is planned for release in December 2009.

The survey was undertaken in both hardcopy (via Bloodline) and online using Survey Monkey with an even distribution of responses (109 responses) across four regions.

The most valued programs and services were support (Outreach Service), education and practical assistance (regional camps, printed resources) and advocacy with government and health care providers. Connections made through HFNZ with similarly-affected people and families were identified as a key source of support.

Personal need was identified as a key factor in the way members used services. Reasons for non-attendance of programs and services were time commitments and that they were not applicable to a current need.

Areas suggested for further focus included communication (including electronic information); resources (awareness and education) and support for families.

Haemophilia Foundations need to regularly keep in touch with their members. The preliminary findings from New Zealand are similar to anecdotal reports from foundations in Australia, however they have the added strength of the data from the survey. It will be interesting to review the final report and consider the implications for Australian foundations.

#### **Note from Editor:**

Haemophilia Foundation Australia has a plan to undertake a survey of database members in the first half of 2010 and is currently scoping the design of the project.

#### **A retrospective audit of yttrium synovectomies at The Alfred** ~ Dr Anne Powell

Yttrium synovectomy is indicated for sub acute arthropathy in a target or problem joints characterised by repeated joint bleeds and synovial thickening. Treatment consists of an injection of a yttrium isotope (Y90)

into the affected joint space and, depending on the circumstances of the joint and the patient, a short stay (1 - 2 days) in hospital may be required.

Previously in 1987 - 91, 40 joints underwent yttrium synovectomy. The procedure occurred in 20 persons mostly with a severe factor deficiency. No side effects were encountered at the time of injection and subsequently there was a significant reduction in joint bleeds and factor usage.

In 2008, a retrospective audit of 9 patients receiving a yttrium synovectomy was undertaken. Each patient had 1 - 3 joints injected, ankles being most common. In this time only 3 patients reported significant improvement and of the 15 joints injected, two-thirds had either no effect or a temporary effect only.

Previous studies support the use of yttrium synovectomy in target joints. Some of the reasons for the differences from the 2008 review and earlier study are that prophylactic treatment, together now with earlier invention, has possibly decreased the efficacy of yttrium synovectomy over the last two decades. A larger prospective trial is being planned to clarify the use of yttrium synovectomy and identify patient selection parameters for this procedure.

#### **The psoas muscle and sexual health** ~ Matthew Stewart

Matthew Stewart, a Brisbane physiotherapist, recognises that sexual health is a sensitive but nonetheless important issue to be incorporated in a comprehensive care framework for those affected by a bleeding disorder. A chronic disorder may lead to treatments and limitations that have an impact on sexual health and the health-related Quality of Life of those affected. These are issues that need to be considered by all health and allied professionals.

A bleed in the psoas muscle, located in the hip region, may have an impact on sexual activity. Given the preponderance of males with haemophilia and most reported age group for psosas bleeds (17-24 yo), together with anecdotal evidence of common spontaneous

bleeds in that area, psoas bleeds have been associated with rigorous sexual intercourse.

The psoas muscle is close to the femoral nerve and any bleed in that area should be treated cautiously and distinguished from a bleed into the hip joint. Symptoms of a psoas bleed may include: pain; hip flexion and increased spinal lordosis; numbness and weakness in front on thigh. Traditional management plans are effective and include: timely factor replacement; proper rest; and, physiotherapy to restore full strength and flexibility once the bleeding has stopped and the patient is able to lie flat. However, it should be noted that recovery of full function may take up to several months.

Sexual health in haemophilia and related bleeding disorders is affected by a risk of bleeding and may be complicated by joint issues. However, care in this area should not be neglected as sexuality is an important part of well-being and quality of life.

#### **Outcomes after joint arthroplasty or arthrodesis at an Australian Haemophilia Centre ~ Dr Kemble Wang**

Dr Kemble Wang presented an investigation of the outcomes of 86 joint replacements and arthrodeses (fusion) in 55 haemophilia patients at The Alfred Hospital, Melbourne, during 1985 - 2008.

Joint disease is most common in the knees, ankles and elbows of people with haemophilia. Whilst factor prophylaxis has significantly changed the nature and management of the disease, the benefits accrue generally to the very young.

Joint replacement or arthrodesis still remains an option of patients with joint disease, particularly in providing pain relief and improvement in quality of life.

The Alfred study reveals that, whilst the rates of complications due to infection and the need for re-operation are higher and functional outcomes are moderate, patient satisfaction remains high due to the excellent results from the relief in pain. The study reviewed 41 knee replacements, 18 hip replacements,

6 elbow replacements and 21 ankle arthrodesis over a 23 year period.

Complications in knee replacements (21/42) ranged from failure to regain motion (7); infection (6) and post-operative bleeding (4). For ankles, all tibiotalar fusions (9/21) had significant complications with 7/21 requiring revision or re-operation. Only 3/18 hip replacements required re-operation; but, a shorter follow up time was acknowledged. For elbows, 2/6 procedures had complications.

Infection rates of all replacements were within the range of other studies undertaken.

Improvements in post-operative function were variable, averaging 60° for knees with a survival rate for a knee replacement after 10 years greater than 83%.

Nonetheless, patient satisfaction rates were generally outstanding. For pain relief, 97% were either very satisfied or mostly satisfied. For function satisfaction, 76% were either very satisfied or mostly satisfied. Hip replacements scored the highest satisfaction rates, with knees (as the most common replacement) with patients on average more than satisfied. Ankle arthrodesis (21/86) were the third most satisfied. The study also indicated that satisfaction does not seem to fall over the years.

Accordingly, the Alfred study shows that, whilst complications are possible and functional outcomes are moderate, patients are particularly satisfied with the pain relief provided by joint replacement or fusion.

#### **30 years' experience of joint replacements in patients with bleeding disorders in SA ~ Dr Lay Tay**

Dr Lay Tay, Royal Adelaide Hospital, presented a 30 year view of treatment protocols and joint replacements for patients with bleeding disorders in Adelaide from 1980 to April 2009.

Treatment is individualised depending on severity with target factor levels and monitoring. A multidisciplinary approach between haemophilia and orthopaedic teams is undertaken with close coordination on the day of surgery.

Discharge usually occurs at day 10 with treatment continuing at least until day 21 in mild haemophilia and a reducing target dose until day 31 for severe haemophilia.

An almost equal division between hip (22) and knee (21) replacements, together with one (1) shoulder replacement occurred over the period. A total of eight (8) joint revisions occurred between 4 and 11 years. Whilst the average age of the patient was 55 yo, ages ranged from 35 - 83 years.

### **Saturday 10 October 2009**

**Concurrent 2  
Living with HIV  
Chair: Alex Coombs**

**Psychosocial aspects of disclosure  
~ Alex Coombs**

**Personal reflections  
~ Matt Powell**

**HIV in 2009 means viral  
suppression for all. New  
opportunities and new challenges  
~ Dr Mark Kelly**

**Positively addressing personal  
barriers - lets talk about.... sex,  
disclosure & relationships  
~ Georgia Ash**

*David Stephenson (QLD) David Stephenson is a Committee Member of Haemophilia Foundation Queensland (HFQ) and HFQ delegate to Haemophilia Foundation Australia Council*

At the recent Haemophilia conference the session 'Living with HIV' brought together some impressive professional presentations and personal stories about living with HIV in 2009.

#### **Disclosure**

How do people with bleeding disorders and HIV experience disclosure? Is it a simple choice of, to tell or not to tell, or a more complex and confronting issue – and what feelings do people have about disclosing a viral infection as well as their bleeding disorder? Alex Coombs from the Alfred Hospital in Melbourne took the audience through some case studies giving a perspective to HIV disclosure in the bleeding disorders community. He described disclosure

as not being a 'one-off event', but rather a process that people go through over their lifetime.

Do you need to tell others? Alex highlighted the significant variations between state and territory laws concerning disclosure of your positive HIV status to sexual partners, and the possible penalties for HIV transmission. Somewhat confusingly, there are potentially two types of laws involved. These are the public health laws and the criminal laws of each state and territory. He drew attention to the web site [www.thinkagain.com.au/whosays1.htm](http://www.thinkagain.com.au/whosays1.htm), which gives an outline state-by-state of HIV disclosure law in Australia.

Making the decision to disclose is a deeply personal one and may require careful consideration. Alex raised several questions to consider. When you think about who you are going to tell, also consider who can help you with this. If you decide to tell, where will you do this? The message was to plan the time and location, giving consideration to all the aspects and possibilities that may arise, how the person might react, making sure the place is comfortable, private and emotionally safe, and thinking about what support all parties may require and what support is available. Ask yourself why you want to tell them and if they really need to know. Think through what difference it will make to everyone involved – is there a concern they may break your confidence? It's always a good idea to go into a situation having thought about how people may react and being prepared for the potential reactions. This could mean rehearsing a script beforehand about what you are going to say. After disclosure, you may find you take on the role of educator. If you have suitable information on hand this can help with the person's fears and other responses.

The case studies gave an insight into individual experiences: "Frank" who had told no one except his father, who lives in another country, and feared people would be able to tell he has HIV from the physical signs of facial wasting; "Wayne", who initially avoided sexual relationships and then when he

began being sexually active, did not know how to tell his partners – at one stage his condom broke and he had to disclose and to his surprise the reaction was very supportive; "Kane", a young man with haemophilia who discovered his partner was HIV positive and, after some time and thought, continued the relationship.

Alex's presentation was followed by personal reflections on disclosure and HIV from Matt, a young man with haemophilia who contracted HIV as an adolescent but was not told he was HIV positive until his 16th birthday. Matt described the impact of this on his development as a young adult and on his relationships – the effect of seeing himself as the "human skittle" in the Grim Reaper HIV campaign of the time – and his journey through hopelessness, emotional turmoil and anger to personal crisis, and from there to making a new way for himself, marriage and starting a family. Matt's presentation was a powerful story of the impact of the "invisibility" of HIV. He pointed out the difficulties for young HIV positive men with haemophilia of sex being a taboo topic; that doctors did not raise it (apart from saying 'use a condom'), and that this left challenging emotional and developmental issues untouched and unresolved. He hoped that by sharing his experience it may give some insight and have relevance for others dealing with these aspects of HIV.

### Viral Suppression for All

In 2009 most Australians with HIV can expect to achieve complete viral suppression of HIV due to a range of new HIV drugs and, along with this, improvement in their immune system, increased life expectancy and quality of life. Dr Mark Kelly from the AIDS Medical Unit in Brisbane outlined the new treatments and how they work, complete with a video showing the HIV drugs and the different points they attack in the HIV replication process. Even for those who developed resistance to earlier therapies, there are a number of other drugs which are very effective.

Over the last three years traditional AIDS-related illnesses have become

rare. However, some new health concerns have arisen, which are collectively known as serious non-AIDS events (SNAE). The most common of these are cardiovascular disease, liver issues (particularly in those co-infected with hepatitis B or C), kidney problems and cancers. To deal with the range of SNAEs, the HIV care team has expanded to include cardiologists and nephrologists.

How do you maintain your health and prevent SNAEs? The current recommendations are:

- Treat viral hepatitis
- Stop smoking
- Ask your doctor to calculate your global cardiovascular risk
- Have your renal function checked
- Have an assessment of your fracture risk and vitamin D levels.

With the improvements in health and viral load, HIV positive men can now consider fatherhood. Dr Kelly described some options available to couples planning to have children, comparing natural conception to sperm washing, and highlighted ongoing issues in the risk of sexual transmission.

### Positively addressing personal barriers

Living with haemophilia and HIV can mean that many of life's milestones are complicated by medical conditions that often involve open and honest discussions with others. Disclosure can involve potential partners, forming relationships, safe sex, having children. Georgia Ash from the Sexual Health & AIDS Counselling Service in Brisbane finished the HIV session with a presentation on how people manage these personal barriers.

It was interesting to hear that heterosexual couples, where one is HIV positive and the other negative, tend not to know others in the same situation and that the negative partners often rate their health less favorably and can be more affected by depression and stress because of stigma, secrecy, isolation and concerns about their partner's health and future. Communication can often be the best way for couples to deal with this: to talk with each other, listen to and

address each others' concerns, keep everything in perspective, remember why they are together and call on professional help if needed.

It was a bit surprising to hear that in the Australian Pozhet study half of the couples have had unprotected sex in the past although they all do not want to pass on HIV. Contrasted to this was the finding in Mark Kelly's presentation that someone with an undetectable viral load in the blood can still have to a 10% viral load in semen – suggesting that safe sex is still on the agenda for discussion.

## Saturday 10 October 2009

### Concurrent 3

#### Practical Living

Chair: Leonie Mudge

**Superannuation & insurance (Travel & income protection) ~ John Berrill**

**Income support/financial assistance ~ Leonie Mudge**

**Career and employment: challenges and choices panel ~ Mike Holloway, Luke Chipperfield, Robert McCabe**

*Martin Raspin (HFV) Martin Raspin is a Committee member of the Haemophilia Foundation Victoria (HFV)*

Leonie Mudge, Social Worker at Royal Prince Alfred Hospital in Sydney chaired and provided an introduction to this session. It was a very important topic for the large audience and for me, as the day to day challenges of balancing work and health needs are of increasing relevance.

Leonie opened her presentation with a wider definition of Health, as expressed by the World Health Organisation (WHO) in their 1948 constitution...

'Health is the state of complex physical, mental & social well-being and not merely the absence of disease'.

And this from the WHO's 1986 Ottawa Charter:

'Health is a resource for everyday life,... a positive concept: emphasising social & personal resources, as well as physical capacities.'

The WHO Commission into the Social Determinants of Health increased our understanding of the role of the social conditions underpinning good health. Things like suitable work, transport and personal mobility, freedom from distress, access to resources, social inclusion and support, freedom from addiction, positive early life experiences and an appropriate level of control over the above factors.

Leonie then touched upon the United Nation's 'Convention on the Rights of Persons with Disabilities', which was ratified by Australia in July 17, 2008, and provides a tool with which we can challenge all levels of government to finally move away from the language of welfare, into a rights based mind set.

Under the Convention on the Rights of Persons with Disabilities, Article 19- Living independently, Article 20- Personal Mobility, and Article 27- Work & Employment are especially relevant.

The next speaker was John Berrill, a Principal at law firm Maurice Blackburn who has 15 years experience in superannuation, insurance and financial services law. John has a long interest in the rights of people living with chronic illness, and has worked with the bleeding disorders community. He has also developed education material and facts sheets which can be found on the Chronic Illness Alliance's online resource, [www.chronicillness.org.au/workwelfarewills](http://www.chronicillness.org.au/workwelfarewills)

John Berrill talked about how unstable health may necessitate dropping in and out of work, which then raises the spectre of financial problems. Or illness may require a temporary or permanent move from full time to part time work, alternative duties or perhaps some workplace modifications.

There is no obligation to disclose your illness to a new, prospective or current employer, but that may be easier said than done. You may even be asked to undergo a medical examination in some instances.

What then are our rights? Is my employer obliged to grant me time off if I need it?

These issues, and others, are fundamental to people living with

haemophilia, or any chronic illness. Importantly, there are laws that apply to these scenarios. Relevant Federal legislation is the Disability Discrimination Act, which has recently been amended.

An employer must now make reasonable adjustments to accommodate a person's disability, and remedies for unfair dismissal provide prohibition on adverse action against employees, because of disability.

On a State level assistance may be possible from an Equal Opportunity Commission.

For many of us, our health challenges may mean we do not work until the retirement age. This can create a poverty trap. Death and disability insurance, as part of superannuation, are designed to be a remedy. Superannuation became compulsory in 1992. Beneficiaries are insured under 'group insurance policies'. If you need to leave work prematurely, the type of superannuation coverage you have becomes extremely important.

It seems that a big change has occurred as a result of increased competition between industry superannuation funds and the amount of coverage available for death and disability has increased significantly.

Early access to superannuation for financial hardship, on compassionate grounds or in the event of total and permanent invalidity is possible with many superannuation funds. People living with a bleeding disorder may be covered for this.

Key message? Check out what your super fund is, and what insurance cover it includes. You should get advice as it may be a very good idea to move to an 'industry super fund', if you are not already in one.

Industry funds offer

- early access to super
- access on compassionate grounds
- access on financial hardship grounds
- total & permanent disability coverage

Importantly, income protection insurance may be useful for those of

us requiring a reduction, or temporary cessation, in working hours to accommodate treatment for hepatitis C or HIV.

Before he finished his presentation, John Berrill encouraged the audience to look carefully at superannuation, and to get legal advice. Companies such as his can provide legal advice to members of our community on such issues.

Following this, Leonie Mudge presented briefly on support mechanisms and safety nets for people who may fall out of work, such as the disability pension.

Key message here? It's a complex system, so use your social worker!

Then we were treated to three personal testimonials.

The first came from Mike Holloway who now lives in Brisbane. Mike has been in work for thirty-five years, working part time for the last sixteen.

There's been great resilience demonstrated in Mike's personal

history. He is of an age where the treatment options available to him early in life were pretty rudimentary, and largely inadequate. I greatly admired his toughness, and stoicism and capacity to keep going. An inspirational story.

Luke Chipperfield is a thirty-one year old civil engineer from NSW who's been able to turn his life long interest in construction into a meaningful and rewarding career.

This is despite being advised in his youth, by well meaning types, to only pursue work in 'public service corporations' which were deemed to be more 'haemophilia friendly'. These people also told Luke to work part time. Luke knew though, that he was capable of mixing it up in private enterprise, gave it a go, and hasn't looked back. Luke now oversees major projects in a field he enjoys.

Luke has had no qualms about disclosing his haemophilia to employers and also underwent interferon therapy, whilst remaining at work. I'm happy to report Luke's

treatment was a success, though he 'had to take two months off at the end.'

His advice? 'Consider the benefits of working from home when you need to, if it's at all possible.

Lastly, Robert McCabe from Perth spoke to us. Robert is a young lawyer at Slater & Gordon.

His career advice? Simple. 'Focus on your interests. Set your goals, align your resources and identify your steps. The planning process is key and setting goals is important. It's also good to know what support structures are available to you (unions, volunteer organisations for example) for peace of mind.

Robert reminded us that improvement in care has resulted in improved opportunities for people with haemophilia. We are resilient and good at self advocacy which we have learnt though our experiences.

Cheers to that, Robert! **H**



# WORLD FEDERATION OF HEMOPHILIA ADVOCACY WORKSHOP IN MONTREAL



*Peter Fogarty*

I attended the World Federation of Hemophilia (WFH) Advocacy Workshop for established National Member Organizations held 24-25 September with Gavin Finkelstein, HFA President and Sharon Caris, Executive Director. This was my first NMO experience with the WFH, and I had high hopes based on the reports of previous HFA representatives to these sorts of meetings. Whilst many NMO meetings and workshops are larger and more structured, the smaller, looser, and more intimate nature of this event allowed for a different type of interaction.

Participants at the Workshop included NMO's which were similar in that they came from countries with a high level of health care and considerable capacity for advocacy in their country. Gathered together were Haemophilia Foundation of New Zealand (represented by Deon York, President and Belinda Burnett, CEO), National Hemophilia Foundation, USA (represented by Val Bias, CEO and Johanna Gray, Advocate), Canada Hemophilia Society (represented by Pam Wilton, President and David Page, Executive Director), Irish Haemophilia Society (IHS) and the European Haemophilia Consortium (EHC) (represented by Brian O'Mahony, Executive Officer, IHS), and Claudia Black (Executive Director) and several Regional Program Officers of WFH.

Each of the participating NMOs had been asked to prepare two presentations - a snapshot of advocacy experiences in their country which I presented on behalf of HFA, and another outlining an advocacy case study from their country which was presented by Gavin Finkelstein on our recombinant lobbying campaign. However, I was 'lucky'


enough to do the very first presentation of the entire workshop. Jetlagged, tired and with clothes I had worn for over 48 hours (thanks to LAX baggage handlers!), I started slow, but managed to provide a coherent snapshot of where HFA fits in to the organization of the Australian health system, and its history of advocacy. It is always difficult being first, especially in such distinguished company, but in the end, the result was good.

Next was Val Bias from NHF who talked about advocacy work in the United States. Some of the recent work has included major challenges around access to treatment including health insurance and lifetime caps on medical claims, HIV visa restrictions and a number of other areas. The NHF is very well resourced and wired in to the complex world of professional lobbyists within the US political system. Overall the USA experience is a completely different battleground to the one that we operate within.

Deon York spoke about the New Zealand landscape, and despite their geographical closeness to us, I learnt a large amount about the difference in public health just across the Tasman from Australia.

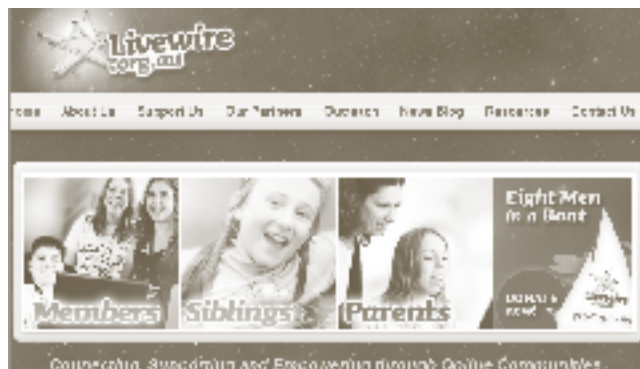
Brian O'Mahony spoke next about the work of the European Haemophilia Consortium which works to provide an additional level of support to European NMO's for their lobbying campaigns. As an umbrella organization, it provides support for countries both within and outside of the EU and operates broadly yet on a small budget. It has organized conferences and provided statements on the principals of care for use by NMO's as part of their larger advocacy campaigns.

Pam Wilton for the Canada Hemophilia Society spoke at length about the campaigns the Canadians have been involved in over the years dating back to the 70's when they first lobbied for comprehensive treatment centres to their work in the 2000's on recombinant product reimbursement. Pam detailed a range of tools, techniques and approaches used by the CHS to achieve their goals over the years. Her presentation highlighted in a very definable and meaningful way how we all interact with each of our governments in a similar way.

In summary, the presentations highlighted how similar many of our experiences have been, sometimes at different times, even though there are regional differences, and we may have different political landscapes, health system structures and local culture. The main message was that for successful advocacy we must be trained, knowledgeable and confident to be on the front foot when dealing with governments and health department officials. The ability to identify a problem before it arrives, and be forearmed, is definitely a plus in any advocacy campaign. This is important at a global level as well as at a very local level when a patient organization is working to improve treatment, care and services for people with bleeding disorders in its national or regional environment. 

# LIVEWIRE.ORG.AU

Suzanne O'Callaghan



Delegates had an opportunity to try Livewire out at the recent 2009 Haemophilia Conference Exhibition where the Livewire team had a stand with a live version of the web site communities. Youth delegates and parents showed quite a lot of interest. Livewire is an initiative of the Starlight Foundation, aimed at giving young people with chronic health conditions, serious illnesses or a disability and their families ways to connect with each other online in a safe and positive environment. For young people and their siblings the focus is on fun and entertainment, with games, news, competitions and interesting chat sessions; for parents, the opportunity to share experiences and information. HFA is a member of the Livewire Affiliate Partner Program and has developed a Memorandum of Understanding with Livewire.

Livewire now has three online communities:

**Members:** available to young people 10-21 yrs with a bleeding disorder

**Siblings:** available to brothers and sisters 10-21 yrs of a person with a bleeding disorder

**Parents:** available to parents of a person with a bleeding disorder

## How do you register?

Livewire is distributing registration packs at Haemophilia Foundation events where they are invited to demonstrate Livewire and through HFA and Haemophilia Centres. These have specific registration codes for bleeding disorder

community memberships. If you would like a registration pack, contact HFA or talk to your Haemophilia Centre. Otherwise you can download registration forms directly from the Livewire web site – for more information, check the Livewire page on the HFA web site under *Kids and Youth – Fun Stuff*.

So far a number of young people with bleeding disorders and their siblings and parents have registered – there is now a bleeding disorders group in the Members Section where young people with bleeding disorders touch base if others are online. They can join the group by selecting “bleeding disorders” when they register. If you are currently using Livewire, we’d be interested to hear your feedback!

## What does the MOU involve?

HFA and Livewire co-ordinate development and promotion through their national offices. This means that when state/territory Foundations want to have Livewire at their Christmas Party or Family Camp, they organise it through HFA, which enables HFA and Livewire to make sure messages and information are consistent and up-to-date and that the current registration packs are distributed. HFA has consulted with haemophilia health professional groups about Livewire – who have been very positive - and is working with them to develop information on bleeding disorders for Livewire and training for Livewire’s moderators and chat hosts. Livewire also took the opportunity to highlight bleeding

disorders during Haemophilia Awareness Week and Chris Poulton, a young man with haemophilia from Victoria, was the chat host guest and talked with Livewire members about his involvement in the Victorian bushfires.


How is it best to make Livewire available to the bleeding disorders community? HFA and state/territory Haemophilia Foundations have been discussing this over the last year. The consensus was that most effective ways would be:

Livewire to demonstrate their online communities at local events where young people and/or parents would be present

A newsletter article by a young person with a bleeding disorder on their experiences with Livewire

Checking with specific young people to see whether they are interested in trying Livewire out.

As a result state/territory Foundations have booked Livewire for a number of local events in the next 6 months. HFNSW was the first with a Livewire presentation at the Family Camp and several young people and their parents registered.

If you would like more information about Livewire – or are volunteering to write about your experiences on Livewire – contact HFA on 1800 807 173 or [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or check the Livewire page on the HFA web site ([www.haemophilia.org.au](http://www.haemophilia.org.au)) under *Kids and Youth – Fun Stuff*. 



The festive season is upon us, with lots of eating and drinking – why don't you incorporate Global Feast in your celebrations....

Global Feast is a fundraising opportunity for Australians to raise funds which will be used for people with bleeding disorders around the world who need our help.

Without proper treatment for their bleeding disorder, most children with severe haemophilia will die when they are very young. An estimated 400,000 people worldwide are living with haemophilia. 75% of people with bleeding disorders throughout the world are undiagnosed and untreated, particularly in countries where health care is not well resourced. WFH is striving to close this gap. Australia is one of the fortunate countries where people with bleeding disorders receive high quality care and treatment. We can all make a difference by working with World Federation of Hemophilia (WFH).

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

All monies will be donated directly to WFH. WFH will use these funds to provide safe and effective blood treatment products free of charge to people in urgent need. WFH works in more than 50 developing countries providing 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 Natashia at HFA on 1800 807 173 or [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au).

Joan organised a Middle Eastern dinner with 17 family and friends and in total raised \$355 for Global Feast. **H**

# US HIV TRAVEL BAN TO BE LIFTED

*Suzanne O'Callaghan*

On 30 October 2009 United States President Obama announced that the 22-year ban on travel to USA by people with HIV would be lifted early in 2010. Obama said that the ban had been "a decision rooted in fear rather than fact" and that "we talk about reducing the stigma of this disease and yet we've treated a visitor living with it as a threat."

Originally the ban was introduced during the 1980s when there was widespread fear that HIV could be spread by physical or respiratory contact. The US remains one of only a handful of countries that bar people with HIV from entry. US public health officials have long stated there was no scientific or medical basis for the ban. Because of this restriction, no major international AIDS conference or international Congress of the World Federation of Hemophilia has been held in the US since 1990.

In July 2008, under George Bush's presidency, Congress began the process to remove the ban by repealing the law which excluded people with HIV from visiting or immigrating to the US. The next step was to remove HIV from the list of communicable diseases that mean a person is unable to enter the US. The US Centers for Disease Control (CDC) approved the removal of HIV from the list on 2 November 2009. In January 2010, after a routine 60-day waiting period, the final procedures to remove the ban from the regulations can be implemented.

Under the previous regulations, HIV positive people could obtain an HIV waiver for travel to the US for business, conference, family reunion, or pre-approved medical grounds, but the procedure was so complicated that many felt it was not worthwhile.

HFA will review and confirm the new administrative procedures for entering the US for an HIV positive person with a bleeding disorder once the ban has been lifted.

The confirmation that the ban will be lifted in January 2010 has been celebrated by HIV organisations worldwide – and will be good news for HIV positive people with bleeding disorders who plan to travel to the US in the future. **H**



Ms Jurarat Suriyathai and Ms Wanna Sopittikul are members of the Thai Hemophilia Patient's Club. They are each mothers of a child with haemophilia and live in regional Thailand with their families. Jurarat and Wanna are trained nurses who have worked hard to progress treatment and care for people with haemophilia in their local area and are valuable members of the Thai Patient's Club. Their visit to Australia was a part of the 2007-2010 Action Plan between the National Hemophilia Foundation of Thailand, Thai Hemophilia Patient's Club, Haemophilia Foundation Australia and the World Federation of Hemophilia. The visit to Australia for Ms Jurarat Suriyathai and Ms Wanna Sopittikul was timed to enable attendance at the 15th Australia and New Zealand Haemophilia Conference and the Haemophilia Foundation Australia (HFA) Council Meeting and Annual General Meeting which followed.

# THE TWINNING PROGRAM – THAI REPRESENTATIVES VISIT TO BRISBANE, AUSTRALIA 6 - 14 OCTOBER 2009

*Jurarat Suriyathai and Wanna Sopittikul*

We arrived in Brisbane two days before the Conference and met with health professionals at the Queensland Haemophilia Centre at the Royal Brisbane and Women's Hospital and Royal Children's Hospital. We observed that a range of services are available for haemophilia patients and people with haemophilia have a choice of plasma derived or recombinant clotting factor and may be treated with regular prophylaxis. There is enough clotting factor and many patients receive this via a home delivery service, and regular reviews are arranged at the haemophilia centre to ensure patients have the care and treatment they require. All of these services are supported by the government budget. An internet web based program has been developed to register all patients in Australia on the Australian Bleeding Disorder Registry.

Our visit included meetings with haemophilia nurses, doctors, physiotherapists and social workers, and the hospital blood bank where clotting factor and cryoprecipitate and other blood products are stored for people with other conditions as well as haemophilia. There are also other stocks of clotting factors in other places, including at the Australian Red Cross Blood Service Blood Bank to make sure there are strong supplies of haemophilia products for all the patients.

Our impression is that there is a good supply of clotting factor, and that patient's quality of life is very good. In Australia many people with haemophilia can plan to go to work or to school. We have learned a great deal about the good model and system for haemophilia care in Australia.

On the day before the conference we were able to help the HFA staff make last minute preparations for the conference. We helped with packing conference bags and preparing rooms for meetings and conference sessions.

We attended both days of the 15th Australia and New Zealand Haemophilia Conference. The conference offered an opportunity for not only the healthcare professionals but also patients, parents and relatives and other volunteers to share their valuable experiences. Some of the valuable sessions for us included the state-of-the-art academic knowledge; psychological care for haemophilia patients, parents empowering parents [PEP], prophylaxis treatment guidelines, hepatitis C treatment and care, and the importance of comprehensive care for people with haemophilia. We have learned many aspects of haemophilia care including the valuable discussions during the conference.

After the conference ended we participated in the Council Meeting of HFA. We had also been invited to make a presentation on the activities

of Twinning Program of Australia-Thailand, 2007-2009". All the Council members were interested and there was good discussion about the work between HFA and TPC. We presented information about the work done in Thailand over the last two years to increase the number of patients on the registry and improve access to treatment. We described the camps we have run in different parts of Thailand to help people learn more about hemophilia and how to care for themselves better.

We have learned that the strength of HFA comes from leadership with good vision, continuous cooperation of the committee, continual support from the government and fundraising, and efficient full time and part time staff at the HFA office. HFA provides ongoing information to members including newsletters, website, and also through events such as Hemophilia Awareness Week 11-17 October 2009, which had the same theme of Life Challenges like the conference. We noticed that all Council members could participate in the meeting and were encouraged to express their opinion. There is also a good plan for fundraising and donor mailing.

The Australian parents, physicians and health care providers have a good medical care system for haemophilia and the different parts of the community work together



Lauren Qld, Kim Vic, Jurarat TPC, Zoe Vic, Wanna TPC, Jane Vic.

closely. Volunteers are well supported and there is good medical care and strong government support. In Australia there is sufficient clotting factor to treat patients and some families have more than one child with haemophilia, and patients and families usually have a good quality of life. In contrast, family planning is a strong consideration in Thailand because we have limited resources and limited clotting factor.

We enjoyed our 9 days in Australia and these are some of our lasting impressions of our visit:

- 1) the welcome and greetings from everyone in Australia
- 2) the excellent medical care system for people with haemophilia
- 3) the high quality of life for people with haemophilia
- 4) the strength of HFA
- 5) the good teamwork of HFA administration
- 6) the new knowledge and experience we learned from the conference and meeting people
- 7) a special moment to remember the people in the haemophilia community who have died
- 8) the democratic process in the meetings

And.....

- 9) the Jacaranda trees in Brisbane in

October are very beautiful with their purple flowers!

We hope that some of the lessons and experiences of what we have learned may be implemented in Thailand to improve hemophilia care to the patients. It will be important for many organizations including the National Hemophilia Foundation of Thailand, TPC, the government, health care providers and volunteers to work together.

We are grateful for the support, kind help and warm hospitality from Council members, volunteers and staff from Haemophilia Foundation Australia, and the support from WFH, National Hemophilia Foundation of Thailand and Thai Hemophilia Patient's Club and the health professionals and others who assisted in making our visit a success. **H**

**In Australia many people with haemophilia can plan to go to work or to school. We have learned a great deal about the good model and system for haemophilia care in Australia**

# Life Challenges

## Haemophilia Awareness Week 11-17 October 2009

HAW aims to raise community awareness about haemophilia and other bleeding disorders in Australia.

HFA and Haemophilia Foundations around the country worked together to develop a campaign to raise awareness about inherited bleeding disorders. Thank you to individuals and organizations and the many individuals who helped promote the week with information stands and fundraisers in many different places around Australia.

Donna Field organized "Paint the town red" in Neerim South during Haemophilia Awareness Week. Donna placed posters, balloons and promotion items around the town and ran a sausage sizzle on Saturday and best dressed in red competition. Thank you to Donna, her family and the local community for their support

Next year HAW will be celebrated from 10-16 October 2010.

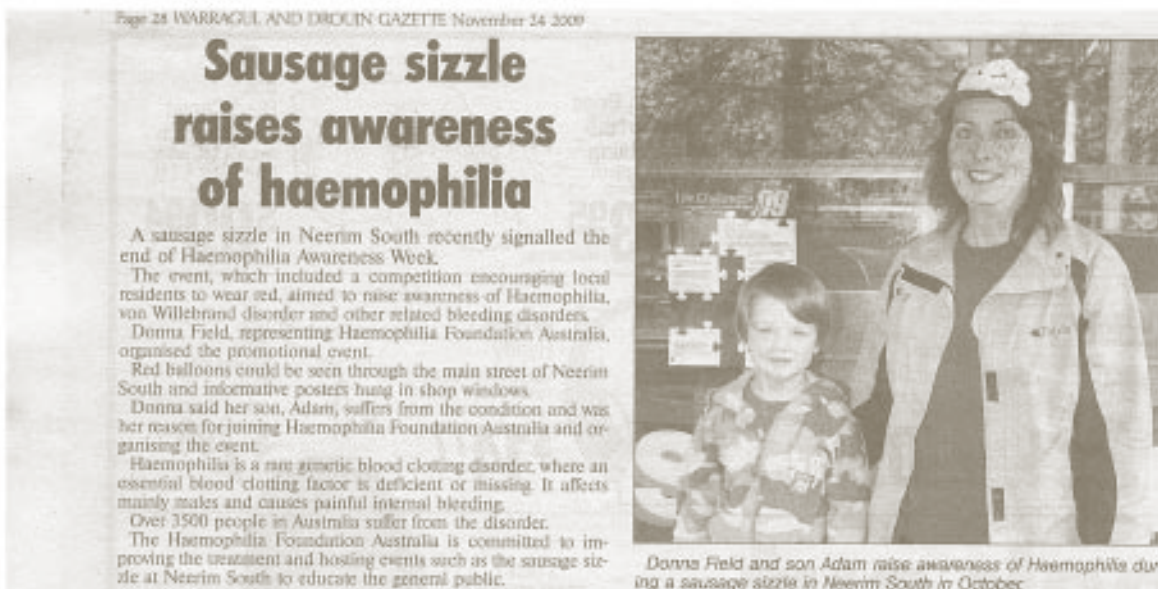
### COLOURING-IN COMPETITION

Congratulations to the following winners -

5 and under: **Caleb**, QLD

6-9: **Samuel**, NSW

10 and over: **Georgia**, NSW



# PLANNING FOR A NEW SCHOOL, KINDERGARTEN AND HOLIDAYS

Sharon Caris

If your child is starting at a new school, kindergarten or crèche soon, you will probably have started planning by now! Transition to a new education facility does not need to be an ordeal for you or your child. As your child may be the first child with a bleeding disorder the kindergarten or school has worked with, carers will appreciate you working with them to ensure they have an understanding of his/her care needs and how to deal with problems should they occur.

Your haemophilia centre staff can help you to gather together the information you might need for carers and teachers about the care or support plans for your child. HFA has printed materials that may assist too!

## Planning travel and holidays!

If you are going interstate or overseas during the holidays you should have made arrangements for supplies of treatment product by now. Don't forget to start your planning early with your haemophilia centre to ensure you have sufficient clotting factor and equipment, other medicines and medical letters etc to take with you. If you are going overseas you will need to ensure you have the necessary customs and quarantine documents for leaving Australia with treatment product, and for returning to Australia and for the countries you will be visiting. Even if you are in transit through a country, remember there may be documentation requirements to carry your clotting factor, needles and other medicines with you through security/quarantine/customs.

Make sure you select carefully where you will travel, especially if you might need medical assistance. Check

whether there is expertise in the care and treatment of people with bleeding disorders in the places you are visiting, and how you would access these services. Be aware that treatment may be limited, unavailable or unaffordable in many countries. Make sure you have appropriate insurance and a plan in the event that you are unwell or have an accident.

If you have been issued with additional supplies of clotting factor for your trip, make sure you take care of it when you are travelling and that you bring any remaining product home with you – you will not be issued with more product on your return if you took larger quantities than your usual supply away with you for that period.

Make sure you contact your treatment centre staff well in advance so they can help you with your travel plans. HFA can also provide more information about your planning for overseas travel. **H**

# ADVANCE YOUR PASSION AWARDS

The Baxter Healthcare **Advance Your Passion** Awards were presented to three teenagers in Sydney in November. Together with one additional recipient in New Zealand, they had been selected from a number of applications by Australians and New Zealanders. **Advance Your Passion** was launched in Australia and New Zealand by Baxter Healthcare in 2008 and is for young people with a bleeding disorder, who are aged between 14 and 21 years of age to advance their lives in areas they are passionate about.

## The 2009 Australian winners were:

Liam James, for support for his motorcycle repair business and archery training. Liam has a passion for motorbikes and hopes to begin a motorbike mechanic apprenticeship soon. He has also become proficient at archery and is keen to pursue both interests.

James Horton has a passion for cricket and is participating at a high level in junior cricket in his region and hopes to take his cricket further. His award is for cricket coaching and equipment.

Daniel Muszynski already plays in a band in venues in his region of NSW. His passion for music and his band lead to his **Advance Your Passion** Award which will be used for a new drum kit.

# DAMON COURTENAY MEMORIAL ENDOWMENT FUND OPEN



**Hemophilia**  
World 2010  
Congress

Buenos Aires • ARGENTINA  
Saturday, July 10 - Wednesday, July 14

The Damon Courtenay Memorial Endowment Fund (DCMEF) was established as a perpetual Trust in 1993 to be administered by Haemophilia Foundation Australia (HFA) by Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon.

The income from the DCMEF investment is distributed every 12 -18 months. A distribution of trust income is expected to be made in May 2010.

DCMEF income can be distributed for care, treatment, education and welfare services for people with bleeding disorders and/or their families, and for education programs and other activities of HFA and member Foundations.

Applications are invited from people with bleeding disorders and/or their families.

Please note that applicants/beneficiaries must reside in Australia.

Applications must be on the application form which can be obtained from HFA by email on [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or phone 03 98857800 or download from HFA website [www.haemophilia.org.au](http://www.haemophilia.org.au)

**CLOSING DATE 30 APRIL 2010** H<sup>i</sup>

## HAEMOPHILIA FOUNDATION RESEARCH FUND

Grants will be available in early 2010 for medical, scientific or social research which will improve outcomes for people with haemophilia, von Willebrand disorder or related inherited bleeding disorders, and/or medically acquired blood borne viruses.

A total amount of \$15,000 is available for one or more projects to be undertaken over the next year. Funds may be applied to projects part funded by other grants.

Application form and conditions of funding may be downloaded from Haemophilia Foundation Australia website at [www.haemophilia.org.au](http://www.haemophilia.org.au) or contact:

### Haemophilia Foundation Australia

1624 High St  
Glen Iris 3146  
T 03 9885 7800  
F 03 9885 1800  
[hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

**Closing Date: 31 March 2010** H<sup>i</sup>

Have you thought of going to the next World Congress?

What about submitting an abstract?

The XXIX International Congress of the World Federation of Hemophilia will be held in Buenos Aires, Argentina, from Saturday 10 July to Wednesday 14 July 2010.

The congress will bring together delegates from around the world to take part in a diverse and exciting program. Sessions cover medical, multidisciplinary and laboratory science issues, with topics of special interest for people with bleeding disorders, members of national haemophilia organisations and health professionals.

On Saturday delegates can participate in the very popular free Pre-Congress workshops and sessions, including sessions for specialist nurses, physiotherapists and social workers. These offer delegates valuable skills and knowledge to integrate into their own work and communities once they return home. Pre-registration is recommended.

Each congress day begins with two plenary sessions led by some of the world's most distinguished researchers, physicians, and community leaders. The plenaries have a focus on current and future treatments, ageing, von Willebrand disorder, mild haemophilia and women.

General sessions will be in 6 concurrent streams and include state-of-the-art symposia, presentations, and "Meet the Experts" sessions on highly topical issues across a wide range of subjects related to living with bleeding disorders, providing services and care and community development.

If you are interested in submitting an abstract, check the topics in the Medical and Multidisciplinary Program and consider what you may have to contribute.

Abstract deadline: 15 January 2010

Registrations close: 14 May 2010

Visit [www.hemophilia2010.org](http://www.hemophilia2010.org) for more information. H<sup>i</sup>



THE  
VISION AND LEADERSHIP  
AWARDS

The Haemophilia Foundation Australia Vision and Leadership Awards were developed by Haemophilia Foundation Australia (HFA) four years ago to enable people who are affected by a bleeding disorder to seek and achieve new goals in their lives. The 2010 funding round opens in December 2009.

The Awards program is funded by an education grant from Wyeth Australia. A panel has been established by HFA to consider applications and monitor the Awards program.

People affected by haemophilia, von Willebrand disorder and other rare inherited bleeding disorders of all ages are eligible to apply.

This is a chance for you to do something you have always wanted to do, but not been able to do because you have not had the financial capacity to support your personal goal.

It might be for an education activity or special project to enhance your personal development or career, or attend a conference or program to enhance or develop new skills for leadership and participation in the bleeding disorders community.

What would make a difference in your life? Consider applying for one of these Awards to help you achieve success or reach a new goal or objective in 2010.

Five Awards of \$2,000 are available for applicants in either of the following categories:

Young men and women aged 15-25 who have a bleeding disorder or who are affected by bleeding disorders

Adults aged 26 yrs and over (men or women) with a bleeding disorder or who are affected by a bleeding disorder

Applications must be received by 31 March 2010 by email, post or fax to:


**Haemophilia Foundation  
Australia**

1624 High St, Glen Iris VIC 3146  
F: 03 9885 1800  
E: hfaust@haemophilia.org.au

For further details and application form see the HFA web site [www.haemophilia.org.au](http://www.haemophilia.org.au) or email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or phone the HFA office on 03 98857800. 

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## GENE THERAPY: CLINICAL TRIAL

Professor John Rasko is the Director, Cell & Molecular Therapies and the Sydney Cancer Centre, Royal Prince Alfred Hospital, and Head of the Gene & Stem Cell Therapy Program at the Centenary Institute. He contributed to the March 2009 edition of National Haemophilia and presented at the recent HFA Conference in Brisbane in October. Prof Rasko described a clinical trial open to suitable severe haemophilia B patients in Australia. If you want more information about participating in this clinical trial contact the Haemophilia Treatment Centre at Royal Prince Alfred Hospital (02) 9515 7013. 

## NATIONAL HAEMOPHILIA FOUNDATION RAFFLE

The raffle was drawn, Friday 30 October 2009 at 1624 High St Glen Iris VIC at 4pm (EST). All winners have been notified.

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### 1st PRIZE ~ SONY DSCW 2900s Digital Camera RRP \$529.00

Description: Digital Camera kindly donated by Midland Retravision

Winner: Ticket No 1504  
– J Barnard WA

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### 2nd PRIZE ~ Overnight Accommodation at Travelodge RRP \$250.00

Overnight accommodation for two people in a Travelodge Hotel of choice (Sydney, Melbourne, Perth, Brisbane, Darwin, Rockhampton and Newcastle) valued at \$250. Accommodation package kindly donated by Travelodge Hotels

Winner: Ticket No 2048  
– L Manganaro WA

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### 3rd PRIZE ~ i-Pod Shuffle RRP \$62.00 & iSUBSCRIBE! voucher RRP \$50


Mini i-Pod Shuffle 1GB and iSUBSCRIBE! voucher redeemable online. Voucher kindly donated by iSUBSCRIBE!

Winner: Ticket No 0252  
– J Furmedge VIC

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### 4th PRIZE ~ Natio Pamper Hamper RRP \$100

Natural Australian skincare for men and women kindly donated by Natio

Winner: Ticket No 0479  
– A Naglewicz WA 

# CALENDAR



## Hemophilia 2010 World Congress

Buenos Aires, Argentina  
10-14 July 2010

ph +1 514 394 2834  
fax +1 514 875 8916  
email [hemophilia2010@wfh.org](mailto:hemophilia2010@wfh.org)

## 22nd Annual ASHM Conference

Sydney 20 - 22 October 2010

Phone: 02 8204 0770  
Fax: 02 9212 4670  
email [info@hivaidconference.com.au](mailto:info@hivaidconference.com.au)  
web [www.hivaidconference.com.au](http://www.hivaidconference.com.au)

## 7th Australasian Viral Hepatitis Conference

Melbourne 6 - 8 September 2010

ph 02 8204 0770  
fax 02 9212 4670  
email [info@hepatitis.org.au](mailto:info@hepatitis.org.au)  
web [www.hepatitis.org.au](http://www.hepatitis.org.au)

## Corporate Partners

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

Among our valued donors are our Corporate Partners which provide unrestricted grants to support HFA programs.

**Baxter**

**CSL Bioplasma**



**Wyeth**

## Season Greetings

The HFA office will be close on the afternoon of Wednesday 23 December and will reopen on Monday 4 January 2010. Please leave a message on the answering machine, however if the matter is urgent please call Sharon Caris on 0410419914



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