

National



Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 171, September 2010



Hemophilia World Congress 2010

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



World Congress 2010

CONTENTS

2	Haemophilia Conference in Sydney In 2011 HFA Fundraising – Tax Appeal 2010	15	Updates – Women, Bloodborne Viruses and Posters
3	Hemophilia 2010	17	Issues in Living with Bleeding Disorders
4	Buenos Aires: Tango, Three Tenors, and "Treatment For All"	19	Growing Up with a Bleeding Disorder – Children and Parents
6	Hemophilia 2010 – An Interview with Gavin Finkelstein	22	Psychosocial Aspects of Sexuality
8	Global NMO Training	24	World Congress 2014 Ensuring Supply
9	New Online Communications Technologies	26	HAW Update Vision and Leadership Awards
11	Hemophilia 2010, Buenos Aires: a Personal Perspective	27	To Paris with Love
12	Recognising Excellence	28	ASHM Conference We Want Your Feedback! Calendar

Haemophilia Foundation Australia

Registered No.: A0012245M
ABN: 89 443 537 189
1624 High Street Glen Iris,
Victoria, Australia 3146
Tel: +61 3 9885 7800
Freecall: 1800 807 173
Fax: +61 3 9885 1800
hfaust@haemophilia.org.au
www.haemophilia.org.au
Editor: Sharon Caris



HAEMOPHILIA CONFERENCE IN SYDNEY IN 2011

The 2011 Australia and New Zealand Haemophilia Conference will be held at the Novotel, Sydney Olympic Park in Sydney, 20 - 22 October 2011.

HFA is currently establishing committees to plan for the conference. Conference sessions will cover clinical and psychosocial aspects of living with bleeding disorders and treatment and care for bleeding disorders. As usual there will be sessions which feature current issues and debates of interest to patients and their families, health professionals, government officials and industry.

In a new joint initiative with Haemophilia Foundation of New Zealand we are also planning an Inhibitors Workshop for people affected by inhibitors to be held after the conference. This will be for patients with inhibitors and their families who wish to learn more about up to date treatment and care and improving quality of life. Some funding will be available for people to attend the workshop.


For inquiries about the conference contact Sharon Caris at HFA on 03 9885 7800

or email hfaust@haemophilia.org.au

For conference updates visit www.haemophilia.org.au 

HFA FUNDRAISING - TAX APPEAL 2010

Haemophilia Foundation Australia made a special fundraising appeal in May to everyone on our database. Over \$40,000 was raised which will help us to provide our vital programs and services to people affected by bleeding disorders and their families.

Thank you to each person who made a kind donation. 



HEMOPHILIA 2010

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

In this issue of National Haemophilia, HFA delegates at the WFH Congress describe some of their experiences and give reports of meetings, workshops and presentations during the Congress. H



BUENOS AIRES: TANGO, THREE TENORS, AND “TREATMENT FOR ALL”



Maria Wensing

What a thrill it was for me to go to Buenos Aires, Argentina, as a delegate representing Australia and our haemophilia community at the 2010 World Congress. I am grateful to HFA and HFACT for their support to enable me to attend the Congress and for the wonderful opportunity to experience the haemophilia community at a global level for the very first time.

Upon arriving at Buenos Aires, I spent the first two days with Sharon Caris from HFA at the township of Pilar, just outside Buenos Aires where the NMOs (National Member Organisations) were having their pre-congress meetings. We were there to promote our bid for the 2014 World Congress to come to Australia. After the NMO meeting we returned to Buenos Aires.

Our hotel in Buenos Aires was in the centre of the city near the Plaza de Mayo, a plaza that commemorates Argentinean independence and where the famous Pink Palace is located. It was at this Palace where Eva Peron stood on the balcony to give her famous address to the people. I found the local people to be very friendly and hospitable. This vibrant city is often described as the “Paris of the South”.

IMPRESSIONS OF THE CONGRESS

It was a wonderful experience and there were just so many highlights that

it is hard to know where to begin! I was quite overwhelmed by the sheer size of the congress – over 4,300 delegates from over 115 countries, and described as “the biggest world congress to date”. With peoples from all over the world, there was great cultural diversity, and being in Buenos Aires, I could not help but sense and feel the excitement and atmosphere!

OPENING CEREMONY AND WELCOME RECEPTION

The Opening Ceremony and the Welcome Reception featured a variety of dance styles including the exciting tango. Mark Skinner, the WFH President, gave a moving opening address to welcome everyone. He emphasized that “WFH’s mission to improve and sustain care” went beyond haemophilia to incorporate advocacy and support for all people with inherited bleeding disorders.

The motto of WFH “Treatment for All” really stood out to me as this encompasses everything important for all people with bleeding disorders: proper diagnosis, management and care by a multidisciplinary team of trained specialists, and safe and effective treatment. The WFH’s vision is for treatment to be available for everyone, regardless of where they live. This is such a heart cry and one

that I immediately felt connected and committed to.

VOLUNTEERS, DISPLAYS, POSTER VIEWING

The congress was helped along wonderfully by what seemed to be countless and cheerful volunteers of all ages, helping and providing any assistance with a smile. There were fantastic state-of-the-art interactive and informative displays located throughout the Exhibition Hall from pharmaceutical companies and sponsors and there was a comprehensive exhibition of posters on display.

The place was a-buzz with people coming and going, and throughout the course of the day there were tango and t’ai chi lessons, the musical interludes adding to a friendly and exciting atmosphere.

EXHIBITION BOOTHS

I really enjoyed meeting and sharing experiences with the NMOs with booths and displays at the congress, including our host country Argentina, Ireland, Tunisia, Algeria, USA, and of course our close neighbours, NZ! It was also great to meet WFH staff at their booth which had interesting information about the work of WFH throughout the world. There was a large map of the world and we were invited to make a donation and place a pin on the map where we came from



Far left
Street scene in
La Boca



Left
(L-R) Jonathan
Spencer, Ann
Roberts, Suzanne
O'Callaghan, Maria
Wensing at the HFA
exhibition stand



Far left
Deon York,
President HFNZ,
with colleagues
at the HFNZ
exhibition stand

Left
(L-R) Gavin Finkelstein,
Maria Wensing,
Michelle Sullivan,
Peter Fogarty at the
Congress Dinner

– it was great to see the stack of pins on many of the countries including Australia and I placed a pin there for Canberra.

We had a roster for the HFA booth each day and answered questions about treatment and care in Australia and how HFA and the State/Territory foundations work together. We had supplies of education resources to hand out. The booth became quite a meeting place for our HFA team and for other Australians at the congress which helped foster a good spirit between us all.

A WIN FOR SPAIN

As I speak Spanish, some of my most memorable times at the congress were meeting and chatting with many of the Spanish speaking delegates and NMOs and helping HFA representatives with translation. It was exciting to join the Spanish contingent to watch the final of 2010 World Cup and great fun to be with the Spaniards as they celebrated their victory with singing, dancing and flag waving!

CULTURAL EVENING

As part of the Congress one night we were treated to a cultural evening of sumptuous local food and wines and warm Argentinean hospitality. There was live Latin music, song and dance at its very best, including the famous fabulous tango! Wonderfully

choreographed dance styles were showcased from regions throughout Argentina telling their stories with passion, humour and joy. The stage was ablaze with colour and the dancers wore gorgeous costumes. I was totally captivated by the unbelievable display of excellent, first class talent before my eyes.

THE FAREWELL DINNER

The Farewell Dinner at the conclusion of the congress included fine dining and musical entertainment by the "The 3 Latin Tenors", and needless to say they were magnificent. After speeches and acknowledgements came a presentation with photographic images of the delegates of the congress, set to a beautiful song that brought tears to my eyes (as I could understand it!) called "Color Esperanza" (meaning Colour of Hope). I found out later it was sung by a famous Argentinean singer, Diego Torres. The evening continued into the night with dancing for all the young at heart!

THE MELBOURNE BID FOR 2014

It was such an honour and joy to be part of the team in assisting HFA to promote Melbourne as a venue for the 2014 congress. HFA and the Melbourne Convention Centre & Visitor's Bureau put forward a convincing proposal at the General Assembly to the NMOs including a beautiful, exciting,

presentation of the city of Melbourne and surrounding regions, the Australian culture and landscape. We all felt very proud and humbled to witness the moment of the announcement that Melbourne had been chosen; it was an emotional and exciting experience for each of us!

The Congress was a wonderful and memorable experience. It gave me new insights and awareness to the issues faced by people with bleeding disorders from all around the world and I was left with a deep sense of gratitude for the quality products and health services we are privileged to have in Australia. I came away with a greater appreciation of the global family of haemophilia, and with increased awareness that there is still a lot of work to be done. I am inspired and motivated to continue to work towards achieving the vision and goal of "Treatment for All". **H**

HEMOPHILIA 2010

– AN INTERVIEW WITH GAVIN FINKELSTEIN

Hemophilia 2010 was Gavin Finkelstein's fourth World Congress. As President of Haemophilia Foundation Australia (HFA), Gavin's role at the Congress also involved him in meetings with WFH and other haemophilia organisations about joint projects and some of the work HFA is involved in. Gavin spoke with Suzanne O'Callaghan, HFA Policy Officer, about his reflections on the World Congress.

Suzanne: What stands out in your memory of the World Congress?

Gavin: Coming from a country with a small population, and therefore relatively few people with bleeding disorders, it is an amazing experience to go to a huge conference where the whole focus is on haemophilia and other even rarer bleeding disorders. At every World Congress, I have always been struck by the camaraderie, enthusiasm and excitement that everyone shares at the meeting. I remember at the first World Congress I attended, a shiver went down my spine when I looked around at the sea of people around me – patients, doctors, industry and government people – who had all come together for one thing: to make it a better world for people with bleeding disorders. The whole experience is very motivating to continue your work when you return to Australia.

Suzanne: What key achievements were you part of during this World Congress?

Gavin: The World Federation of Hemophilia celebrated the successes of its Twinning Program with some special activities during the Congress. It's immensely positive to see what the Twinning Program has been able to achieve by pairing a more established haemophilia organisation or a treatment centre in one country with an organisation or a centre in another country that is ready to develop its haemophilia treatment and support.

Over the years that HFA has been involved in twinning with Thailand, I have learned a great deal about how helpful this Program can be for both of the twins. During the Congress HFA and our Thai twinning partners met to review our work together. Before getting involved in our Twinning Program, I knew very little about Thailand and its healthcare system. Sharing knowledge and experiences has been a great way to understand and learn about each other.

I have been really impressed to see how much Thailand has been able to do to increase access to haemophilia treatment with such limited resources. Great progress has been made with the patient registry. The registry has been really important to demonstrate the need for government funding for additional clotting factor. So many more patients have access to treatment and some patients now

have access to prophylaxis; and the government is willing to purchase more clotting factor. Parents are keen to meet with other families and it is amazing to see how far some travel to attend patient meetings and to provide support and education to each other. It's quite inspiring to see what has been achieved. With Twinning you really get a sense that there is a world of haemophilia. You see each other face-to-face a couple of times a year as a result of the program and you build friendships on a personal level. The benefits and ongoing relationships are fantastic for everyone involved.

Peter Fogarty (HFA Vice President) and I represented HFA at the WFH General Assembly after the Congress. This is an important business meeting for WFH and National Member Organisations and several important matters were discussed about each of the WFH program areas. For us, another major achievement was at the General Assembly when HFA won the bid to hold the 2014 Congress in Melbourne. I had spent some time talking with people who regularly attend congresses to find out their thoughts about attending a Congress in Australia, and answering questions about Australia. Because of this I met many more people from other countries than might usually be the case. It is really valuable to hear the experiences, challenges and successes of others, and learn from them.



Left
(L-R) Mark Skinner,
WFH President,
Gavin Finkelstein
and Zev Fishman

Below left
National
Hemophilia
Foundation of
Thailand and HFA
delegates at the
Twinning Meeting
at Congress

Right
Argentinean
dancers at the
Cultural Event



Suzanne: What were your main impressions from the Congress sessions?

Gavin: I think the presentations highlight the degree of professionalism and skill in managing bleeding disorders in many countries now, no matter what resources they have. I went to several sessions where there were presentations from people from more highly resourced countries, such as those in northern Europe, USA, Canada, England and Australia, along with less well resourced countries, such as Egypt, India and the South American countries. These countries do some wonderful things with limited amounts of clotting factor and facilities. Some have developed successful ways to reduce the risk of bleeding during surgery, while others have developed treatment regimens, with emphasis on physiotherapy, and lifestyle management for example, to help manage bleeds and joint damage and improve quality of life. The comparisons put our own experiences in perspective; and remind us we should never be complacent about the resources we have and the importance of maintaining the level of services in Australia and access to adequate supplies of safe clotting factor. We should appreciate what we have, manage it carefully and use it for the greatest benefits.

I was also interested to see a more holistic approach to care being promoted. For example, the pain management session I attended looked at the long-term management of pain associated with joint problems and covered a range of management options tailored to the individual that don't necessarily involve medication, including using ice or meditation.

Suzanne: What did you enjoy most in the social program?

Gavin: I found that during the social events people really relaxed and were more informal. It was an opportunity to talk to people about how they live, what their personal interests are, to get to know them better and reinforce relationships made at previous Congresses. Often you swap email addresses, and then can share useful information in the future. For example, Canada has recently completed their strategic planning process and they were happy to send it to us for us to have a look at.

When you are at a Congress, you often don't have time to leave the convention centre to see the city for yourself. But at the World Congresses, the culture and colour of a country is brought to you with the cultural events – and at Buenos Aires, it was certainly spectacular! The sensuality of the tango dancing

was stunning and, not being a dancer myself, I was impressed at how they managed such intricate steps.

Suzanne: Why do you think the World Congress is important?

Gavin: The World Congress gives you perspective on where Australia stands in the world and how fortunate you are living in this country. It's a very humbling experience. You meet some absolutely wonderful people who inspire you by the way they deal with their lives and the happiness they have in sharing knowledge and experiences, when their lives are so much tougher than ours.

The Congress can also be very exciting – you see all the new innovations and the latest in treatment and care. And most importantly, there is always hope at the end of it. **H**

GLOBAL NMO TRAINING

Peter Fogarty



Delegates at NMO Training 2010

It was my great privilege to attend the WFH Global NMO Training in the lead up to the World Congress. The first time you go to a world congress, it is a truly mind expanding event. The same can be said for NMO training.

The World Federation of Haemophilia (WFH) is the world level peak body for people with bleeding disorders and has as its goal, 'Treatment for all'. The member organisations of WFH are known as the National Member Organisations (NMOs) and represent individual countries from around the world. At the time of writing, WFH has approximately 115 NMOs. I was nominated by HFA to attend the three days of experiences. It is not quite training, but rather lectures and workshops; but the opportunities that lie beyond the boundaries of the formal program are what made the experience truly extraordinary.

The formal parts of the training this year included Suzanne O'Callaghan, Policy Officer at HFA, presenting in a session on utilization of new media channels. Suzanne presented a plenary session on how HFA uses internet technologies at HFA, including Facebook and Livewire.

Once breakout sessions occurred, around 115 delegates broke into four streams: two for the emerging countries, one for the Spanish speakers, and one for the developed world. I was in the group that included Canada, New Zealand, United Kingdom, Sweden, South Korea, Turkey, France and others.

In our breakout sessions, we tackled issues such as conflict resolution within NMOs, and twinning. Both of these sessions provided a healthy level of discussion and it was good to see the level of passion that exists.

Additional plenary sessions were conducted around the WFH strategic

plan, youth issues, and details for the general assembly which was held at the end of the congress.

To say that NMO training is intensive is to undersell it. You live, eat, sleep, drink and watch world cup soccer with your NMO colleagues, and over the course of the three days hear the experiences of so many others to remind us how blessed we are in Australia.

With the bid to hold the 2014 Congress in Melbourne, there was naturally a heightened interest in Australia. This meant questions and conversations with many of the 115 delegates, and learning much about their country and haemophilia organisation in return. In doing this, I have made a large number of new and very special friends which will last for life. **H**

NEW ONLINE COMMUNICATIONS TECHNOLOGIES

Suzanne O'Callaghan



Presenters in the Communications Strategies Session at NMO Training

WFH was keen to promote the potential of web site communications and to explore what various organisations have been trying out with online videos and social networking media such as blogs, Facebook and Twitter.

The Congress in Buenos Aires was my first experience of a World Hemophilia Congress and I was expecting a vibrant and stimulating event. Even so, I was amazed at the diversity of the countries represented and at just how involved all the National Member Organisations (NMOs) were in the presentations, the trade exhibition and strategic discussions and planning that occur during the Congress.

The World Federation of Hemophilia

(WFH) had invited me to present in the online communications session at the NMO Training – a three-day satellite meeting before the World Congress for representatives from national haemophilia organisations worldwide. This was a great honour and I was a little apprehensive about presenting to an audience made up of more than 100 different nationalities, and where there would be simultaneous translation into English, Spanish, French and

Russian. It felt like an invitation to present at the United Nations!

The meeting took place at a hotel in Pilar, a leafy residential area about an hour away from Buenos Aires city. From the moment I arrived, I was aware of a real sense of welcome and enthusiasm to get to know each other and share experiences. The WFH staff went out of their way to make sure that we were all comfortable and meal times became an opportunity for everyone to sit with each other in the hotel restaurant and chat – sometimes in multiple languages at once. While we were waiting for the first sessions to start, I even found myself having a conversation with my neighbour, a Spanish-speaking member from Argentina, via the Babelfish translator on his laptop.

Online communication strategies

WFH was keen to promote the potential of web site communications and to explore what various organisations have been trying out with online videos and social networking media such as blogs, Facebook and Twitter. Elizabeth Myles and Sarah Ford from WFH spoke about some of WFH's recent online projects and particularly the success of the WFH Facebook page and the 2009 World Haemophilia Day video podcast "Together we care", which they marketed heavily through online networks. It raised an interesting question about the way we raise

>>

WFH had asked HFA to present on our work with HealthInsite and Livewire. Because we have limited staff and resources, HFA has taken the approach of working in partnership with organisations such as HealthInsite and Livewire, who have the resources or expertise we lack.

awareness in the wider community – should “viral marketing” (eg, marketing that involves passing messages from one person to another online) now be one of our promotional tools?

WFH had asked HFA to present on our work with HealthInsite and Livewire. Because we have limited staff and resources, HFA has taken the approach of working in partnership with organisations such as HealthInsite and Livewire, who have the resources or expertise we lack.


HealthInsite is an Australian Government online health information service. Through its partnership with HealthInsite, HFA is able to link the wider community to HFA's high quality information on bleeding disorders and follows international guidelines to make its information accessible to people with disabilities. Working in partnership with Livewire has enabled HFA to provide safe, fun

and supportive online communities for young people with bleeding disorders, their siblings and parents.

Delegates were quite interested in my presentation and asked questions about the technical side of online partnerships and the review procedures we use to keep our information up-to-date, or to let web site users know that information is being reviewed.

Zikai Huang from China presented on his haemophilia organisation's web site which has a very popular question and answer section for doctors and patients. I was quite interested in this as it is very different to the approach in Australia where doctors prefer to discuss their patient's health issues with them individually, face-to-face and in confidence. We talked about this afterwards and he explained that in China there are so few haematologists with experience in bleeding disorders that this is one of the only ways patients and

their families have to get accurate and appropriate information about their bleeding disorder and complications. They can also see other people's questions and learn from reading the answers.

Val Bias, the Chief Executive Officer of the National Hemophilia Foundation (USA), also spoke about some of the NHF's web 2.0 projects. The www.hemaware.org web site is particularly well-developed, and has topical articles, personal stories, videos, polls and links to NHF programs and fundraising events. NHF also manages a Facebook page and a Twitter site. 

HEMOPHILIA 2010, BUENOS AIRES: A PERSONAL PERSPECTIVE

Zev Fishman

Zev Fishman and Gavin Finkelstein try out the infrared football game at the World Congress trade exhibition



My name is Zev Fishman and I am a 59 year old man with severe haemophilia A. Last year HFA submitted a bid to the World Federation of Hemophilia (WFH) to host the World Hemophilia Congress in 2014. In November, a WFH delegation visited Melbourne to see if Melbourne could meet all the requirements to host the event. At that time I had reason to be in a wheelchair and HFA asked me to test out disability access for the facilities, both in a wheelchair and on crutches. Then HFA also asked me if I would like to be a part of the HFA delegation to the Congress. My partner Judith and I were delighted to go. A no-brainer really!

For those of you who don't know me, let me give you a short history of my life. Born in 1951, I was diagnosed with haemophilia at two years of age, with no previous history in the family. I was treated at the Children's Hospital in Melbourne until the late 60s when I was transferred to the Alfred. I was given my first factor replacement at the age of about 16. Hence, I have that distinctive aged haemophilia walk, with not much happening below the waist!

I was married in 1975 and have 3 wonderful healthy adult children and a one-year-old grandchild. I have always worked and still run a full time business.

My story is no different to many people I know who have haemophilia. I have had my share of problems related to this disorder. There have been times where I have felt badly done by, felt sorry for myself and thought how unlucky I am.

Well how unlucky am I? Let me tell you about what I took away from the Congress.

What I realised is how lucky I am to have been born in Australia. This was my first exposure to the world family of haemophilia. From the first day at registration I felt a belonging, a feeling that all of these 4000+ delegates had some sort of connection to this bleeding disorder. I was full of excitement; I didn't want to know about the cure or the world's best practice for orthopaedic surgery. I needed to talk to people with haemophilia; I needed to know their story. I wanted to stop that bloke who walked just like me. I wanted to tell him that I understand what he has been through and talk to him about the treatment that he uses and the surgical procedures he has had.

Well, it wasn't like that. One of the first facts I learned at the very first Plenary was that only 30% of all people with haemophilia have treatment or are diagnosed. I couldn't believe that was true – what do they mean, 70% of people

>>

I was heartened by what is being done by so many to turn things around. I realised that one reason WFH puts on a Congress every two years is to raise funds to develop programs that help communities with no or little access to treatment.

don't get treatment? Everyone in Australia has product in their fridge if they want to. I know what it's like not to have treatment. You kick a football and you have a bleed in your knee and you're in bed for two weeks. You could die from some simple knock. What do they mean 70% of people with haemophilia don't get treatment!!


What became very apparent to me was that so few really benefited from all the knowledge and expertise evident at the Congress. I found it very upsetting to know that 70% of all people who have haemophilia struggle with issues that I did before the 1960s: when will this bleed stop? When will the pain go away? Why can't I do things that everyone else can? It seems ironic that some of the issues dealt with at these conferences are related to the introduction of HIV and HCV to treatment products. Most of the people in the world with haemophilia don't have these problems - small consolation, I suppose.

As hard as it was to deal with the thought that so many don't have treatment and resources, I was heartened by what is being done by so many to turn things around. I realised that one reason WFH puts on a Congress every two years is to raise funds to develop programs that help communities with no or little access to treatment. I also realised the importance of the Twinning programs, and how much effort is put in by WFH and participating countries. Twinning is a wonderful way to support the countries that still need to build expertise and knowledge and get access to treatment.

I met some wonderful health professionals who give freely of their time, expertise, knowledge and money to help the poorest of communities. It's hard to believe that there are still problems with the medical expertise to diagnose children with haemophilia.

I met families from developing countries who had lost children to haemophilia. My heart went out to them. I almost felt ashamed of all the privileges I had back at home. They were lobbying to improve conditions and facilities in their country.

What an emotion filled week! My thanks to HFA for the privilege of being part of the Congress. We should all make an effort to participate in a World Congress and Melbourne 2014 will be a great opportunity to meet many wonderful people, who are part of this large haemophilia family.

Am I lucky to live in this great country? I think I might bite my tongue next time I want to complain about my treatment! 

Ann Roberts is a member of the HFA Executive and President of Haemophilia Foundation Victoria

RECOGNISING EXCELLENCE

Ann Roberts

The WFH Congress is a time and place where the world haemophilia community - patients, professionals and industry - comes together to try to achieve haemophilia treatment for all. I find it fascinating that such diverse groups can make such positive efforts to understand each other and work towards a common goal.

Even though there are many people who contribute to the work of WFH, there are some organizations and individuals who contribute in an extraordinary way and deserve recognition. I found it very enjoyable and satisfying to be present when WFH made its awards to the volunteers and the haemophilia organisations from around the world who work so hard for the haemophilia community and achieve so much.

This year the International Frank Schnabel Volunteer Award was given to Antonia Luque de Garrido from Venezuela. This award, named after the WFH Founder, is given to an person with a bleeding disorder or a family member who has made a significant contribution toward the WFH mission or goals. The International Healthcare Volunteer Award went to Dr Mammen Chandy from India. This award is made to a haemophilia health care professional whose volunteer work in WFH committees or programs is exceptional.

The Awards Ceremony also included the presentation of the Hemophilia Organisation and Hemophilia Treatment Centre Twins of the Year Awards. The WFH Twinning Program pairs haemophilia patient organisations or treatment centres in developing and developed countries to encourage an exchange of knowledge, experiences and skills. The Program includes training, exchanges, workshops, patient education, and other activities to improve treatment and care for people with bleeding disorders.

THE WINNERS WERE:

Hemophilia Organization Twins of the Year

- Gaborone, Botswana – Philadelphia, USA (2008)
- South Africa – Canada (2008)

Collaboration & Learning Through Twinning

Suwannuraks M¹, Finkelstein G², Caris S², Isarangkura P³

¹ Thai Patient's Club

² Haemophilia Foundation Australia

³ National Hemophilia Foundation of Thailand



Thailand – Australia Twinning

A National Member Organisation (NMO) twinning partnership between National Hemophilia Foundation of Thailand (NHFT), Thai Patient's Club (TPC) and Haemophilia Foundation Australia (HFA) has been an engaging and rewarding relationship for both the emerging NMOs and the experienced NMO. It has strengthened the patient activities of each organisation by:

- Improving communication
- Expanding skills and exchanging knowledge
- Providing new tools for reviewing policies and procedures
- Giving new perspectives on current NMO ways of operating
- Identifying leaders and building leadership skills
- Increasing the confidence of each side of the partnership to represent its members.



Exploring the possibility of twinning

2005-6 Australia (HFA), Thailand (NHFT, TPC) and World Federation of Hemophilia (WFH) meet in Vancouver and Bangkok, Thailand

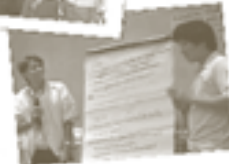
- Learning about health services, the blood service system, government, people with haemophilia and their families
- Twinning funding provided by WFH.



Developing an action plan

2007 Australia (HFA) visits Bangkok, Thailand

- Capacity building: leadership, communication, skills, planning, cross-cultural understanding
- Workshops
- Identifying regional leaders in Thailand to connect with local people with haemophilia



Sharing ideas & experiences

2008 Thailand (TPC) visits Brisbane, Melbourne and South Australia

- Understanding treatment and care experiences in Australia and Thailand
- Sharing ideas on organising patient support activities - family camps, haemophilia community organisation meetings, youth leadership camp.



Strengthening skills & increasing knowledge

2009 Thailand (TPC) visits Brisbane, Australia

- Updating HFA Council on Thai successes
 - Increased access to care and treatment in regional areas
 - Increased numbers in patient registry
 - Stronger case to increase government funding for services and access to clotting factor
- Increasing specialised knowledge about treatment and care in Australia and Thailand
- Participating in a haemophilia conference
- Opportunity for individuals and NMOs to reflect on their own and their organisation's practices and understand the strengths of each approach.



The benefits of twinning

Twinning has been a very positive experience for all partners. The collaboration and friendship between the organisations has led to successful capacity building and has enabled a fruitful exchange of ideas and information. In each organisation leaders have been identified to participate in the twinning visits and workshops and to communicate what has been learned to their own community.

With effective collaboration and a shared commitment to work through communication and cultural differences, NMO twinning can achieve successful and sustainable outcomes.



ACKNOWLEDGMENTS

- The staff and volunteers at the National Hemophilia Foundation of Thailand
- The staff and volunteers at the Haemophilia Foundation Australia
- The staff and volunteers at the World Federation of Hemophilia
- The staff and volunteers at the Thai Patient's Club
- The staff and volunteers at the National Hemophilia Foundation of Thailand
- The staff and volunteers at the Haemophilia Foundation Australia

- Peru – Galicia, Spain (2009)

Hemophilia Treatment Centre Twins of the Year

- Colombo, Sri Lanka – Vellore, India (2009)
- Chisinau, Moldova – Warsaw, Poland (2009)

People involved in WFH Twinning programs also described the benefits and outcomes of their work in a session during the Congress. The importance of involving government health authorities, patients and families, national haemophilia organizations and medical centres, and WFH in twinning programs, and the need to develop reliable and comprehensive national patient registries were seen as critical for progress towards better access to treatment.

Speaking in the session, Prof Parttraporn Isarangkura, President of National Hemophilia Foundation of Thailand, outlined how the Twinning Program with Australia has assisted Thailand to implement its National Hemophilia Care Program and has demonstrably improved quality of life in 78% of patients and their families. Since 2004, hospital stays for people with haemophilia are 42% shorter and hospital admissions have decreased by 23%. The development and benefits of the Thai-Australia Twinning was described in a poster put together by HFA, the Thai Patient's Club and the National Hemophilia Foundation of Thailand and displayed in the poster exhibition. During the Congress, ongoing events were planned in a twinning meeting between Australia, Thailand and WFH. Plans include a workshop in Bangkok and regional outreach visit in Thailand later this year to be attended by HFA representatives.

The HFA experiences in the twinning with Thailand and the reports from the other twins who won Awards are reminders of the benefits twinning can bring to both developed and developing countries. It was heartening to see the very visible

and positive outcomes of twinning and the encouragement given to other countries considering the Twinning Program.

I also came away with some thoughts related to our own treatment experiences and quality of life. Hearing about the treatment experiences of other countries in the work towards treatment for all highlighted for me how important it is to acknowledge the treatment that is supplied free to all Australians with bleeding disorders by Australian governments - and to encourage members to make the best use of treatment to improve their health and quality of life, and act responsibly with their use of clotting factor. **H**

Prof Parttraporn Isarangkura, President of National Hemophilia Foundation of Thailand, outlined how the Twinning Program with Australia has assisted Thailand to implement its National Hemophilia Care Program and has demonstrably improved quality of life in 78% of patients and their families.

UPDATES – WOMEN, BLOODBORNE VIRUSES AND POSTERS

Suzanne O'Callaghan

WOMEN AND BLEEDING DISORDERS

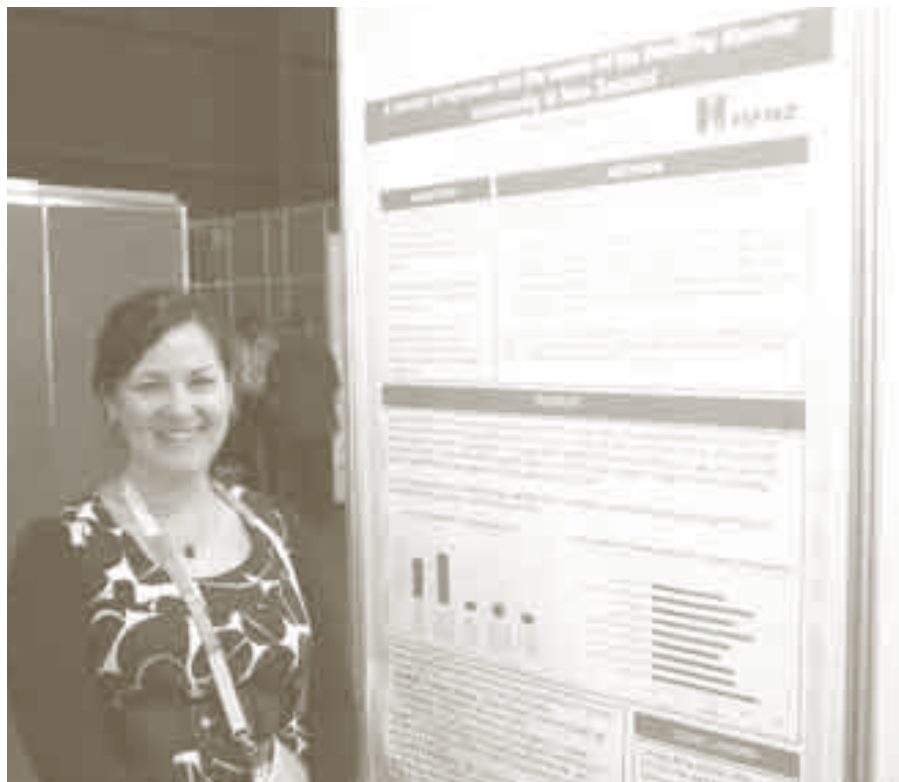
My current work on education materials for women with bleeding disorders has highlighted for me that this is an area that is developing quickly, so I was keen to attend the Pre-Congress session that gave an update on the issues.

Sylvia von Mackensen from Germany and Nicola Dunn from the UK began the session by exploring some of the psychological issues encountered by women with bleeding disorders and their families. They pointed out diagnosing and managing a woman's bleeding disorder improves not only her care but her quality of life. Psychosocial support is also important to help a woman and her partner/family deal with some related issues:

- A girl might share a closer relationship with person from whom she inherited her bleeding disorder, and other relationships in the family might need to be given some care
- Sharing a diagnosis with a new partner has practical implications, such as managing menorrhagia and sleeping arrangements, as well as the need to deal with psychological concerns
- Starting a family can cause a woman anxiety due to fear of bleeding events if she ceases using contraceptives or at delivery
- There may need to be some careful thinking about how to keep a woman's diagnosis a secret from family members if this is important but privacy is difficult.

In the session the world perspective also showed that there can be special issues related to the local community.

Chantal Lauzon from HFNZ with her poster



For example, presentations from Iran and Pakistan reported higher numbers of women with severe VWD and haemophilia due to the number of marriages between close relatives, such as cousins. Ironically, in communities where women with bleeding disorders often experience discrimination, marriage to a cousin who understands bleeding disorders as they are a common condition in his extended family can be more attractive to a woman as it means she will be accepted in her husband's family. Education and outreach programs in these communities have been very effective strategies for improving women's care, quality of life and educational and career opportunities.

The session also referred to newer and more sophisticated methods of diagnostic testing around the world, which have meant that some women who were initially diagnosed as Type 3 VWD have been diagnosed more

accurately and reclassified – for example, some have Type 2 VWD rather than Type 3. Other areas such as the safest modes of delivery in childbirth and the role of prenatal diagnosis remain controversial.

HEPATITIS C AND HIV/HCV CO-INFECTION

New treatment and care strategies for people who acquired hepatitis C or HCV/HIV co-infection through their treatment products was high on the agenda at the Congress and there were a number of sessions which focused on this.

International co-infection and hepatitis C experts, Margaret Ragni and Ken Sherman gave updates on the latest in medical issues. Ragni pointed out the importance of having an early referral to a hepatologist and considering treatment at a younger age, especially in HIV co-infection, as people with bleeding disorders were

>>

often infected at a younger age than usual and liver disease may progress faster with co-infection.

Sherman discussed the difficulties in developing new treatments for hepatitis C. He noted that the most advanced new treatments for hepatitis C are combination therapies with pegylated interferon/ribavirin and either telaprevir or boceprevir, which are protease inhibitors. These are likely to be available outside of clinical trial from 2011 in the US.

POSTERS

There were quite a number of posters displayed at the World Congress poster exhibition. I had two posters accepted for the exhibition – one on the Hepatitis C Wellbeing Weekend and the other on the process for developing HFA educational materials. While the presentation time at the poster exhibition was intended to provide delegates with a time to discuss the posters with their authors, it was also a great opportunity to talk with other poster authors. For example, Chantal Lauzon from Haemophilia Foundation New Zealand and I found ourselves grouped with a colleague from Iran and had a very interesting

conversation together about how to promote feedback on resources from our communities. **H**.

Suzanne O'Callaghan beside her poster



For more information on these sessions, see the Congress program and reports on the WFH web site: www.wfh.org. Contact HFA if you would like copies of particular abstracts.

PRE-CONGRESS SESSION

Women and bleeding disorders

QOL of women with bleeding disorders -
Sylvia von Mackensen, Germany

Psychological aspects and long-term management
of women with bleeding disorders -
Nicola Dunn, UK

How to prepare and support affected women to
deal with the medical and the social aspects -
Shirin Ravanbod and Mehran Karimi, Iran

Inherited bleeding disorders - experience as a
patient and a treating doctor -
Susan Halemi, Germany

Management of pregnancy and delivery -
Rezan Kadir, UK

Prenatal diagnosis & PGD: novel technologies/state
of art of PGD in different regions of the world -
Flora Peyvandi, Italy, and Carol Kasper, USA

Women with bleeding disorders -
Andra James and Roshni Kulkarni, USA

Consensus from an international expert panel on
diagnosis and management Preliminary Report from
US CDC data

SESSION S1.2

Viral Pathogens

Impact of HIV on Hepatitis C - Margaret Ragni, USA

HCV Update: Clinical and Treatment -
Kenneth Sherman, USA

Clinical impact of Parvovirus B19 infection -
Jeanne A. Jordan, USA

ISSUES IN LIVING WITH BLEEDING DISORDERS

Jonathan Spencer

I attended the World Congress as a member of the Executive Board of HFA. The World Congress brought together 4,300 people from around the world to hear and discuss the latest developments in treatment and care for people affected by a bleeding disorder. I was particularly interested in some sessions that addressed issues that are relevant to the bleeding disorders community in Tasmania. The comparisons with the Australian situation and common issues also raised some very interesting questions.

INTEGRATING OUTREACH TO WOMEN WITH VWD & RARE BLEEDING DISORDERS INTO NMO STRATEGIES

Population studies indicate that approximately 1% of the general population may be a person with von Willebrand disorder (VWD) and a recent WFH survey (2008) revealed over 52,000 patients with VWD registered worldwide.

Unlike haemophilia which usually only occurs in males, women are equally likely to have VWD. Awareness campaigns for women in Canada, Lebanon, Georgia and Venezuela have indicated that awareness and detection strategies are likely to significantly increase the detection of VWD and also increase the participation of women as volunteers. Some of the strategies used included education of doctors; distribution of information materials to health professionals and the community; and specific presentations and workshops.

In some countries, gender issues and community stigma remain a problematic factor in detecting women with VWD with the effect that women only approach health professionals for diagnosis, treatment and care in the most extreme cases.

Other factors affecting awareness campaigns such as political turmoil and invasion, together with the high personal cost of testing are unknown. While the results of overseas studies should be interpreted cautiously and often reflect the specifics of local populations, it was interesting that over one-third of the women detected with VWD in the Bekaa Valley, Lebanon were type 3 VWD (severe) and that in countries such as Canada, where there are well developed awareness campaigns, bleeding disorders in women may still be significantly undiagnosed.

NOVEL THERAPIES

In a plenary session on novel therapies Claude Negrier noted that improvements in recombinant technology point towards increases in health, quality of life and reduced costs of treatment. In the past, some efforts to create novel therapies using genetic engineering in animals have not proven successful. However, clinical trials and studies are currently underway that may significantly extend the half-life of replacement factor with the result that factor treatment will be longer acting.

These products will be carefully assessed in international trials. During the Congress, results were released of a study showing a three-fold increase in the half-life of a protein (rFIXFc) for haemophilia B treatment, suggesting that future prophylaxis treatment in haemophilia B may be as infrequent as once a week.

Hopefully these studies will continue to provide positive results to improve treatment, care and wellbeing.

ASPECTS OF AGEING

Dr Gerry Dolan noted in his plenary presentation that age-related issues

in haemophilia are relatively new, but welcome as the active life of people with bleeding disorders is extended with safer and more available treatment.

Nonetheless, dealing with concurrent issues of bleeding disorders and age-related issues such as diabetes, heart disease, hypertension, cancer, osteoporosis and kidney failure will be a future challenge for health professionals who may have little experience in managing multiple medical conditions in older patients with haemophilia.

It is likely that substantially more factor concentrates will be used with an ageing population with bleeding disorders and studies suggest that the development of inhibitors may gradually increase with age in patients with haemophilia A. Also, there seems to be minimal difference in the incidence of cardio-vascular disease in people with haemophilia and those without haemophilia.

While more data is needed to investigate any emerging issues, it is important that people with a bleeding disorder receive the same preventive care and health promotion as the general population. The message I took from this session is that having a bleeding disorder does not protect you from the usual age-related issues and regular checkups with your Haemophilia Centre and/or GP are very important as you get older.

PAIN MANAGEMENT AND COPING

Irene Fuchs, a psychologist from Argentina, highlighted that people do not react to an injury or pain in the same way. There isn't an average sensitivity or threshold of pain and the level of pain is partly related to the

>>



Gavin Finkelstein, HFA President, presenting the Twinning poster to Prof Partrapon Isarangkura, President of Thailand's National Hemophilia Foundation

For more information on these sessions, see the Congress program and reports on the WFH web site: www.wfh.org. Contact HFA if you would like copies of particular abstracts.

SESSION 1.6

Integrating Outreach to Women with VWD & Rare Bleeding Disorders into NMO Strategies

Canadian Experience - Clare Cecchini, Canada

Lebanese Experience - Claudia Djambas-Khayat, Lebanon

Georgian Experience - Marina Mdivnishvili, Georgia

Venezuelan Experience - Arlette Ruiz-Saez, Venezuela

PLENARY 03

Novel Therapies - Claude Negrier

personal meaning given to the pain at the moment it occurs. Pain is also related to social, cultural, religious, economic and psychological factors.

European studies show variations in the clinical approach to management in haemophilia. Analgesic use is directed by the HTC in 60% of cases, with 25% by the patient themselves. Pain and use of analgesics (eg paracetamol, NSAIDs, COX-2 inhibitors) is regularly assessed and reviewed when reported; but, very few consultations with pain management specialists are arranged. There seems to be a need for a more systematic approach and evidence-based guidelines.

This session would have struck a chord with many people that have suffered chronic pain. To me, it seemed important that effective pain management is fully discussed with your Haemophilia Centre, recognising that pain can vary with personal circumstances.

SEXUALITY AND BLEEDING DISORDERS

In a wide ranging session on sexuality and bleeding disorders, circumcision, prevention and treatment of STDs and menorrhagia, psoriasis and muscular skeletal problems, and ageing and sexuality were discussed.

Circumcision has cultural and religious significance and is the most common surgical operation in the world. It should be undertaken by skilled medical personnel, usually under a local anaesthesia. Bulent Zulfikar

presented results from a study at a paediatric haemophilia centre in Istanbul, which showed that risks are minimised if the procedure is undertaken early (18-24 months old), when body weight and risk of inhibitors are lower. The severity of the condition will indicate the necessary treatment regime.

Adolescent children (male and female) with chronic illness are as sexually active as their peers. So, it is important that sexual health is incorporated into a model of comprehensive care. Carolyn Francis described a model of the five Ps of taking a sexual history which has been a successful practice in discussing sexual health with young people - partner preference, sexual practice, past history of STIs, protection from STI, prevention of pregnancy. Such discussions may be challenging for both a Haemophilia Centre practitioner and patient; however, a multidisciplinary approach, including obstetrics and gynaecology where necessary, is likely to improve the patient's ability to cope and contribute to their general feeling of good health.

Sexuality is an important element of life and relationships, linking to quality of life factors such as desire and intimacy, self-esteem, being able to relax and cope with complex emotions. Evelien Mauser-Bunschoten from the Netherlands highlighted that changes in male sexuality may arise from ageing, haemophilia related disorders such as haemophilic arthropathy and iliopsoas

muscle bleeds causing loss of function and pain. Also, chronic hepatitis C and HIV may affect sexuality.

I think that a comprehensive care plan needs to include discussions about relationships and emotions, including sexuality. But, I also recognise that these sensitive issues may be a challenge for some. As Mauser-Bunschoten pointed out, in a multidisciplinary approach it is important for Haemophilia Centre professionals to communicate and provide information on the practical aspects of sexuality, including pain management and medication, and refer to sexology or sexual health experts where appropriate.

POSTER - COLLABORATION AND LEARNING THROUGH TWINNING

Haemophilia Foundation Australia; Thai Patient's Club, National Hemophilia Foundation of Thailand

At the Congress poster exhibition Dr Monthon Suwannuraks from the Thai Patient's Club and I presented a poster on the successes resulting from the twinning partnership between HFA and the Thai Patient's Club and the National Hemophilia Foundation of Thailand. The WFH-sponsored twinning program between Australia and Thailand has been operating for several years. The twinning program assists patient organisations to share knowledge and experiences between established and emerging foundations and helps build capacity in the emerging foundation.

PLENARY 05

Aspects of Ageing -
Gerry Dolan

SESSION T3.3

Pain Management and Coping

Physician's Perspective - Alessandro Gringeri, Italy

Psychologist's Perspective - Irene Fuchs, Argentina

Patient's Perspective

Nurse's Perspective - Penny McCarthy, Australia

SESSION W2.3

Sexuality and Bleeding Disorders

Circumcision - Bulent Zulfikar, Turkey

Prevention and treatment of STDs and menorrhagia - Carolyn Francis, USA

Psoas and MSK problems - Greig Blamey, Canada

Hemophilia, ageing, and sexuality - Evelien Mauer Bunschoten, the Netherlands

We had a number of visitors to the poster, and discussed questions about the relationships between the established and emerging twins with one of our haemophilia organisation colleagues whose organization is considering a twinning partnership. An important part of this relationship is not to assume that a model that works well in the established twin will work as well in the emerging twin, but to allow the emerging twin to find their own way to build capacity. A twinning partnership is a two-way exchange that allows both organisations to grow independently. This has been demonstrated very successfully in Thailand. Since 2005, the Thai Patient Club has grown by 100 members a year and now has over 1000 members.

The poster was a collaborative project between HFA and the Thai Patient's Club and the National Hemophilia Foundation of Thailand and was formally presented to the Thai Twinning Team after the poster exhibition. A visit to Thailand by HFA is planned for the later half of 2010. **H**

Michelle Sullivan is a member of Haemophilia Foundation Victoria

GROWING UP WITH A BLEEDING DISORDER – CHILDREN AND PARENTS

Michelle Sullivan

I have been fortunate to attend my first International Congress of the World Federation of Hemophilia. My husband took charge of our two little boys, who both have severe haemophilia A, while I jetted off to Buenos Aires. With his encouragement and the support of HFA I was able to experience the opportunity of a lifetime.

There were so many people to meet, so many stories to hear and so many sessions to attend. I learned a great deal: in particular how far the management of haemophilia has come, how fortunate we are here in Australia in regard to access to treatment options, and how scientific development is working towards better treatment options (for example prolonged half life of recombinant factors, alternative routes of administration of factors, successful clinical trials underway already). Of all the sessions I attended however, it was those where 'real people' spoke about their personal 'real' experiences – from all around the globe - that had the most impact on me.

CHILDREN AND BLEEDING DISORDERS

Cesar Garrido (Vice President of the Venezuelan National Member Organization) described the most common reactions from parents when they first discover their child has a bleeding disorder: "Why me?", "Why my child?", "How will we cope?" He pointed out that a parent's attitude will have more impact on a child than

any other factor, and therefore it is up to us to find a way to come to terms with it and be positive, so that our children will feed off that attitude and not one of fear, anger, resentment or self-pity. Cesar suggested that "the most immediate coping strategies are to understand the condition, learn about the available treatments, and to teach children to participate in their own care".

From a young Serbian mother, Gordana Stevanovic, came the story of her journey since the diagnosis of her now 4 year old son's haemophilia. She spoke of her experiences, and how her attitude was picked up by her son. Her suggestion was to be open and honest with a child's questions and to explain the condition early and as fully as possible. This would help them to build self esteem and avoid any sense of guilt or shame about their bleeding disorder.

What role does a Haemophilia Foundation have to play? Christine Keilback from Canada spoke about the strength that can be gained by becoming involved in your national member organization. By doing so parents can get the information they need, they can meet other families that share in similar experiences, they can learn from each other about how to avoid feelings of denial or overprotective behaviors. Christine also spoke about the benefits of family camps, reflecting on her experience through the Canadian Hemophilia Society.

>>

The multidisciplinary approach to helping children cope with their bleeding disorder was reinforced by Ed Kuebler, a psychologist from the USA: he described how doctors, parents, psychologists and member organizations all have a role to play in helping a child be reassured about their condition and eventually accepting their bleeding disorder.

SPORT

I attended the session on sport with the hope that an expert would make what I find to be a difficult decision for me – ‘should I encourage or even permit my boys to play football?’ (or other particular sports for that matter). I did not get a definitive answer, but I did get a lot to think about. The general consensus was that recommendations are not consistent across the board, and that the ‘most appropriate sport’ does not exist. An interesting point was that the psychological aspect is an important factor in choosing to participate or not. People will often choose to be a ‘black sheep’, rather than heeding the advice of haematologists, orthopaedic surgeons or physiotherapists. Swimming, cycling, walking or tai chi may well be great physically (and that is not to be underestimated) but the argument was put forward that these can be very socially and psychologically isolating options – although in many cases are they the only options?

Dr Alfredo Pavlowsky from Argentina spoke of the overall benefits of exercise in children – improving self esteem, body image, coordination, strength, motor function, as well as the decrease in cholesterol and diabetes risk and keeping body weight controlled. He recommended that in choosing a sport, the type and severity of bleeding disorder needed to be considered, as well as the child's experience of bleeds, their age, their joint and muscle condition and their social/geographical location.

Next to speak was an incredibly motivating man with an amazing story. Martial de Haro, a 53 year old Frenchman with severe haemophilia A, spoke about his journey. In the lead up to 2004 he had developed seized elbows, ankles and knees from severe arthropathy. He had stopped

playing all sports, he had gained weight, he had lost all self confidence, and he was becoming depressed. Then one day in July 2004 he decided that something had to change. So after completing a medical check, consulting a sports doctor, signing the appropriate medical forms, agreeing to not alter his treatment plan and finding an appropriate instructor – he and 3 other men with haemophilia were given the go ahead to try scuba diving. It was a slow, careful and calculated journey, but he has made remarkable progress. To this day he has completed 500+ dives (resulting in no bleeds), he has co-written a book *Scuba diving guidelines for people with hemophilia*, he is considering becoming a diving instructor himself, he sends an annual report to the medical board of the FSDF (French Scuba Diving Foundation), and he organizes annual summer camps for people with haemophilia (PWH) from throughout Europe. His message? After jumping the hardest hurdle – getting the confidence to try something new – he has enjoyed the benefits of sport: developing team spirit, experiencing new emotions, building self confidence, restarting a physiotherapy program, he has lost weight, increased the amount of exercise he does, and has no more isolation/frustration/anger/sadness due to the restrictions on his life.

Martial de Haro's experiences were supported by Sylvia Von Mackensen, a psychologist from Germany. She outlined the results of three studies undertaken in the field, and concluded that socialization and self esteem particularly are the biggest benefits of physical activities and sports.

A speaker from Lebanon gave a different personal story. Elie Khairo is a 25 year old man with severe haemophilia A. Throughout his childhood he had very limited and inconsistent access to clotting factor, and despite his parents encouraging him to keep active and fit so he ‘didn't seize up’, he eventually became wheelchair bound for 4 years with his knees being fused at 90 degrees at one stage. Following surgery to his knees in 1997, and then total knee replacement surgery in 2004, he took a gentle, consistent approach to exercise and has built his way up

slowly with body building. His key: to go slowly and carefully and work up to something, not to be ‘like a bull at a gate’.

So what did I conclude after this session? That sports and physical activities are imperative both physically and mentally, and that kids being kids are probably going to try things anyway. So long as one is sensible and not reckless and embraces the recommended protective measures suggested, then sport can be not just beneficial, but essential.

LIFE STAGES

The session on Life Stages was possibly one of my favorite of the entire congress. It began with the screening of the newly released WFH podcast *Our Lives With Hemophilia: The Stories of Vaibhav and Paul* (available to download via the WFH website) which highlighted how differently haemophilia can be managed in different parts of the world – through the examples of Paul Wilton, a 25 year old man from Canada, and Vaibhav Nehra, from New Delhi, India. Following the screening each of these young men told their stories and spoke of their individual experiences and how different their upbringings and management of haemophilia were – before joining the panel to answer questions from the audience. It was during this session that someone in the audience said that in his country, Romania, seven people had died the previous year from haemophilia – simply because they had no access to treatment and had bleeds that caused their deaths. It amazed me that this could still happen in 2009!

Gabriele Callizani, the president of the Italian Hemophilia Society was next to speak and gave a middle aged man's perspective of living with haemophilia in a developed country, emphasizing the standard of care in Italy. He also spoke of issues associated with the cost and availability and supply of factor concentrates in Italy and other parts of Europe since the ‘global financial crisis’. A contrast to his experience was then the next speaker – Yuri Zhulev, who is also the president of the Russian Hemophilia Society. He reflected on what it was like to live with haemophilia during his era

in Russia, where – in his case – he suffered from social isolation, chronic pain, and growing up he had limited and inconsistent access to clotting factor. He pointed out that it was only five years ago that free of charge factor concentrates became available and that people in Russia had access to prophylaxis.

Finally Gordon Clarke from Belfast in Northern Ireland spoke, giving the perspective of an older man living with a bleeding disorder, in his case, severe haemophilia B. He told of how for the first 20 years of his life there was no factor concentrate, and that by age 11 he had stopped going to hospital as they had “given up”. It was only at age 20 or 21 that he first received factor replacement. Amazingly, in spite of the adversities in his life, Gordon as an adult eventually become the manager of The Belfast Childrens’ Hospital, which ironically was the very same hospital he had spent so much time in and had grown to loathe as a very young child.

What an incredible experience! To hear all of these personal stories from all around the world gave me a new appreciation for how far haemophilia treatment has come for many, and how fortunate we really are here in Australia. More importantly, it also emphasized how much work is yet to be done and how it really is of utmost importance that somehow, someday we really do achieve the ultimate - “treatment for all”. **H**

To hear all of these personal stories from all around the world gave me a new appreciation for how far haemophilia treatment has come for many, and how fortunate we really are here in Australia.



For more information on these sessions, see the Congress program and reports on the WFH web site: www.wfh.org. Contact HFA if you would like copies of particular abstracts.

SESSION S1.3

Helping children cope with bleeding disorders

Strategies for a normal life – Cesar Garrido, Venezuela

Mother’s perspective – Gordana Stevanovic, Serbia

Building acceptance and adaptability in children managing hemophilia: the National Member Organization’s role – Christine Keilback, Canada

Psychologist perspective – Ed Kuebler, USA

SESSION M1.3

Sports: Dangerous, Beneficial or Luxury

Sport in Hemophilia: What is Appropriate? - Alfredo Pavlowsky, Argentina

Personal Experiences/Examples: Scuba Diving - Martial de Haro, France

Psychosocial Impact of Sports - Sylvia von Mackensen, Germany

Youth’s Perspective - Elie Khairo, Lebanon

SESSION W1.3

Meet the Real Experts: Life Stages

Youth Perspective from a Developing Country - Vaibhav Nehra, India

Youth Perspective from a Developed Country - Paul Wilton, Canada

Middle-Age Perspective from a Developed Country - Gabriele Callizani, Italy

Middle-Age Perspective from a Developing Country - Yuri Zhulyov, Russia

Older Perspective from a Developed Country - Gordon Clarke, U.K.

Older Perspective from a Developing Country - Said Ul-Islam, Pakistan

PSYCHOSOCIAL ASPECTS OF SEXUALITY

Alex Coombs



This was my first World Hemophilia Congress since I commenced working at the Ronald Sawers Haemophilia Treatment Centre at the Alfred hospital two years ago. I appreciated the opportunity to experience and be exposed to the international bleeding disorders community and hear about the variety of experiences with access to product and services in different countries, and the topical issues that are often overlaid with individual cultural, religious and political environments. A particular area of interest for me throughout this Congress was that of sexuality and sexual health.

My first day was spent in the psychosocial workshop amongst colleagues from a variety of fields, but primarily social work and psychology,

where the work is focused on providing education and support to the inherited bleeding disorder community. In this workshop speakers from various countries gave a report about their activities on fostering psychosocial involvement in several emerging haemophilia care centres. Several speakers from twinned Haemophilia Centres, who had the opportunity to work in the emerging environments of Minks, Georgia and Jordan, spoke about their experiences of developing a program to plant the seed that comprehensive care is more than meeting the medical needs of the client. The psychosocial education and support role is one that requires clear explanation to the emerging Haemophilia Centre client population. There were many challenges in the haemophilia treatment context for

these workers. As care agents, they needed to be mindful of the cultural sensitivities and differences of working in resource poor environments in comparison to their home countries.

There was an interesting session on sexuality through the "eyes" of a person with a bleeding disorder and the worker's role in addressing this issue with a client. As a group we questioned whose role it is to raise this with a client. Sexuality is a sensitive topic to raise and as psychosocial workers we were reminded that this may be part of our role in working with our clients. This may be achieved by unpacking their experiences progressively and the many challenges of their sense of self and their future outlook as sexual beings. This session focused on the role of the worker and their own level of comfort with the issue of sexuality, which can have a significant impact on the working relationship with the client. It was noted though in general that health professionals lack confidence or a preparedness to talk with a client about sexual health and sexuality. As such, a worker's own level of comfort with sexuality allows our clients to talk openly about sex, sexuality, dating and relationships. Additionally we should also consider the worker's gender and how this may influence the trust and comfort level of the client when beginning a session.

We explored a definition of sexuality as "the quality or state of being sexual" and "the condition of having sex". There are many sexual issues that present themselves through the life cycle of a client as they develop from childhood and mature from youth into adulthood that are also influenced by the cultural and religious

Sexual health and function was seen to be an integral component in the overall health of people with a bleeding disorder.

belief system of the client and the worker. Whilst my focus is in adults, it is important for me to remember the stages of development as sexual expression begins to change over time with the emerging physiological changes that occur that are influenced by hormonal developments. As sexual activity increases through the tentative explorations of dating or the client begins to express themselves sexually, how does the worker raise topics such as, that a bleed might occur? A discussion also ensued around working with the sexual diversity of our clients, and we were reminded to avoid making assumptions of sexual homogeneity. In this respect we should be conscious at our level of comfort in discussing the varying types of sexuality as our clients range from heterosexual, homosexual, bisexual or even asexual. There remains amongst our client population some in varying life stages, who are co-infected with HIV, and/or Hep C, who may also be living with joint damage and associated pain that has created marital strain for the client and their partner.

The theme of sexuality and bleeding disorders was also continued in another session on the last day of the Congress. Sexual health and function was seen to be an integral component in the overall health of people with a bleeding disorder. The integration of sexual health into haemophilia care reminds us that our clients do have sexual lives regardless of their age, and we should also consider the needs of the partner as well as that of the client. Pain and sexual dysfunction associated with an acute bleed may not only have physiological effects but also have psychological implications such as reduced libido,

or decreased sexual function through fear of a bleed reoccurring during sexual activity. This was an area where the multi-disciplinary approach of integrating physiotherapy and the rest of the care team can provide education and support, for example, with regard to sexual positioning and emotional adjustment. Addressing this issue with a client can develop into an exploration of what sexuality does for them. Common responses reported were that it is a form of relaxation; it is used to cope and express emotions; and assists with self esteem. A client's sexuality also enhanced their quality of life by having a positive effect on their emotional wellbeing as well as benefiting a person's heart health and contributing to their life span. **H**



For more information on these sessions, see the Congress program and reports on the WFH web site: www.wfh.org . Contact HFA if you would like copies of particular abstracts.

SESSION W2.3

Sexuality and Bleeding Disorders

Circumcision - Bulent Zulfikar, Turkey

Prevention and treatment of STDs and menorrhagia - Carolyn Francis, USA

Psoas and MSK problems - Greig Blamey, Canada

Hemophilia, ageing, and sexuality - Evelien Mauser Bunschoten, the Netherlands

WORLD CONGRESS 2014

Sharon Caris

An exciting outcome of the General Assembly of the World Federation of Hemophilia (WFH) in July was that Haemophilia Foundation Australia (HFA) was selected as the host country for the 2014 Congress. WFH is already planning Congress 2012 which will be held in Paris, and we will soon commence some of the planning for the Congress to be held in Melbourne in 2014.

The 2014 Congress will be a wonderful opportunity for Australians with bleeding disorders and their families from around the country to attend for "a once in a lifetime" opportunity!

WFH has a well established Congress Secretariat which will manage the Congress planning program. HFA will support WFH and work with the broader stakeholder community in Australia to provide local input to the Congress program, including cultural and social activities.

HFA has made a commitment to assist WFH to make Congress 2014 inclusive, accessible and profitable. In the next year we will establish a range of activities and committees to plan for Congress.

HFA President, Gavin Finkelstein recently said "Congress will be enriching for everyone involved. We look forward to our work with our members as well as Australian health professionals and others who will be involved in the Congress". **H**

ENSURING SUPPLY

Sharon Caris

Treatment product availability in Australia has changed dramatically in recent years and liberated the lives of many people with bleeding disorders and their families. With treatment prophylaxis, treatment product choice, home therapy and home delivery, people with bleeding disorders are now able to manage their lives quite differently to how they may have done before. And, there is a generation of children and youth, and their parents, who have never realised that others before them have lived without enough safe clotting factors and some of the treatment approaches they know so well. The legacy of blood borne viruses and an inadequate supply of clotting factors remains with us as we see a larger proportion of ageing members in our community. Many of these members remember how their treatment product had to be rationed when there was not enough clotting factor for everyone. Many now live with long term joint damage. Fortunately there are now many people who have treated with long term prophylaxis in Australia who do not live with significant joint damage.

The changes and improvements are important. Most important is that there is a secure supply of safe treatment products. For many people there is now some choice about the treatment product they might use and how it is supplied to them. Most people in Australia have come to expect a level of care and treatment equal to the world's best. HFA has encouraged this. We have also encouraged individuals and families to find ways to overcome obstacles that might get in the way of living with a chronic bleeding disorder. We may have even created an impression that life should be no different for a person with a bleeding disorder compared to any other person in the community without a bleeding disorder. But we all know this is no simple thing and it takes great effort for individuals and their families to manage their bleeding disorder and to make the sort of life they want to live into a reality.

Some of the people who have reported their experiences of Congress have told you about their shock to learn about the inequitable distribution of clotting factor around the world. They are heartened by the work being done globally to increase access to care and treatment for those who currently receive little or no treatment, in the way Australians with bleeding disorders have come to expect. They have returned feeling incredibly grateful for the systems we have for providing treatment and care in Australia, and that clotting factors

are provided to all Australians at no financial cost to them because they would not be able to afford to pay for them.

Although HFA's communications often emphasise efforts to increase the supply of safe clotting factors in Australia, and the need for individual and clinical choice, it is important for us to recognise treatment is not just all about clotting factor. We also need a network of haemophilia centres which provide specialist care and treatment, including access to a range of specialist health services which might be needed often or just occasionally. Because of this, HFA is developing a policy about comprehensive care which we hope will be adopted by all stakeholders.

It is important for people to be making decisions about their treatment in association with their treating health professionals. This is particularly important when clotting factor is delivered to a person's home or work to help make life more manageable and convenient, and when a person is treating with prophylaxis. These circumstances should not imply that treatment will roll along without the need for review or change. It is important for health professionals to monitor how their patients are going, and check whether a different approach or dosage may be necessary. This requires recording of clotting factor usage, patterns of bleeding and regular reviews with the treatment team to ensure things are on track or to plan for things that might need to change for better health outcomes and quality of life. An important part of this monitoring also includes making sure clotting factor is used properly and in correct amounts. It is an expensive and valuable commodity, and some of our Congress delegates felt this even more acutely when thinking about how many of the people in the world with bleeding disorders receive no treatment at all.

It is important that people can be certain about their treatment. In Australia most people with bleeding disorders would probably expect to have their treatment product supplied whenever it is needed. This expectation not only includes having regular supplies of clotting factor

for prophylaxis or demand therapy, but may also include additional supplies to cover emergency and joint replacement surgery and for travel, sport and recreation. Some people have clotting factor delivered overseas to enable them to pursue their career or personal travel objectives.

The expectation for certainty is strong in Australia and it is fulfilled. I rarely hear of situations where people cannot receive supplies of clotting factor to their preferred place, and most people can access specialist treatment services. This is important.

I am not sure however, that everyone knows the extent of plans in place to make sure there are adequate supplies of clotting factor in Australia. Haemophilia centres need to predict how much clotting factor is required for their patients and this information must be fed into a state and national supply plan. Although that is a somewhat simplistic explanation, it begins to describe the very complex demand and supply management undertaken by the National Blood Authority (NBA). The NBA does this on behalf of all Australian governments which share the costs of clotting factors, including plasma derived products manufactured in Australia and imported recombinant clotting factor products.

HFA is a part of a large group of stakeholders consulted about demand planning and supply management. It is important that clear and accurate information about the needs of every patient is clearly understood and planned for, as well as for people newly diagnosed, and all who need treatment into the future. Many people in our community no longer need to visit their haemophilia centre as frequently as they may have done before. But they still need to keep in touch with their doctors and other health professionals so their care is managed as well as it can be, and so their needs are known. These days people may even communicate with their doctors and nurses via mobile phone to report and discuss bleeding issues, and to request and order supplies of treatment product.

There are wide ranging reasons for people who use treatment products to be clear about their needs and

accountable as the products are expensive for governments. An issue for delegates of all countries at the Congress is the cost of clotting factor, and how increasing use can be sustained. An extension of this is how governments get best value for money for their expenditure for treatment products for a relatively small number of patients.

Congress sessions on how health technology assessment is used to understand costs and effectiveness of treatment were well attended. This form of evaluation is used in Australia in healthcare and for the evaluation of medicines. Different treatment regimens such as comparing short term and long term prophylaxis or prophylaxis and demand therapy may provide information about the cost and benefits of different approaches and could lead to the development of treatment guidelines and protocols.

The ageing of the bleeding disorders community raises significant new issues, some of which relate to cost and access to services. Improved treatments for bleeding disorders and blood borne viruses results in a positive outcome that people with bleeding disorders are living into old age. This increases the need to understand the impact of chronic conditions such as heart disease, diabetes, cancer and kidney disease and the impact of bleeding disorders. Increased clotting factor usage for surgery and to manage bleeds needs to be factored in to demand and supply planning. Congress sessions which addressed ageing in particular, pointed to this new experience and also for the need for research to understand the needs of our ageing community and to ensure this group in our community receives the same level of health prevention and health promotion services available to the general community.

These considerations need to be discussed and understood, and solid plans need to be put in place to ensure the achievements in this country are lasting and sustainable. **H**



Life Challenges the real issues

Haemophilia Awareness Week 10-16 October 2010

WHAT IS HAEMOPHILIA AWARENESS WEEK?

Haemophilia Foundation Australia and Haemophilia Foundations around the country work together to raise awareness in the wider community, community organisations and governments about inherited bleeding disorders.

The theme this year is "Life Challenges – the real issues" which highlights the real, day to day issues faced by people with bleeding disorders and celebrates the ways they overcome these challenges.

WHEN IS HAEMOPHILIA AWARENESS WEEK?

During the week of 10-16th October a number of local events will take place across Australia including school fetes, sausage sizzles and promotion across schools, hospitals, doctors' clinics and workplaces.

HOW CAN YOU HELP?

There are many ways you can help raise awareness of bleeding disorders during Haemophilia Awareness Week. Here are some ideas:

- set up a stand in your workplace, school, hospital or library
- hand out promotional items in your local area
- assist your local Haemophilia Foundation during the week
- organise a casual clothes day at your workplace or school
- organise a luncheon, sausage sizzle or morning/afternoon tea.

ARE THERE RESOURCES AVAILABLE TO HELP RAISE AWARENESS?

If you decide to organize a local event or want to promote Haemophilia Awareness Week at your school, workplace or community centre, there are a number of promotional items available.

These include wrist bands, stickers, tattoos, posters, balloons, bookmarks, pens, colouring-in sheets and many more. To place an order for items (free of charge):

- download an order form at www.haemophilia.org.au

- call Janine at HFA on 1800 807 173
- email jstaunton@haemophilia.org.au

Get in quickly as stock is limited!

WOULD YOU SHARE YOUR PERSONAL STORY?

We are always keen to hear from people of all ages who are willing to share their personal stories of life with haemophilia. Personal stories are the best way to raise awareness of life with haemophilia – both during Haemophilia Awareness Week and throughout the rest of the year.

If you would be willing to discuss sharing your story, please call Janine at HFA on 1800 807 173 or email jstaunton@haemophilia.org.au

Don't forget to tell us about your Haemophilia Awareness Week activity afterwards.

WHO CAN I CONTACT FOR MORE INFORMATION?

If you would like any information about Haemophilia Awareness Week 2010 please call Janine on 1800 807 173 or email jstaunton@haemophilia.org.au 

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 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.

The Awards are available to people of all ages. Two specific categories have been established to encourage young men

and women aged 15-25 and adults aged 26 yrs and over who are affected by a bleeding disorder to apply.

Applicants were encouraged to consider what would make a difference to their life. The Awards are an opportunity for people to have some assistance to achieve success or reach a new goal or objective.

We would like to congratulate the people who received the Awards. You will find some of their stories in the next few issues of *National Haemophilia*. 

“Go for your dreams and do what you want to do.”

TO PARIS WITH LOVE

Richard Davidson-Lim is a young man with a mission. He has two loves: performing arts and languages. When he heard about his school's exchange program with the world-renowned Lycee Racine School of Performing Arts in Paris, it seemed like the perfect opportunity to bring his two passions together.

Richard is one of the winners of the Vision and Leadership Awards for 2010. He plans to use the Award for an exchange trip to the Lycee Racine in 2011.

Richard attends The Hutchins School in Hobart, which itself has an impressive performing arts program. He first learned about the exchange with the Lycee Racine at an information session when he was in Year 6 and was determined to apply, but has had to wait three years before he was old enough to put in an application: you have to be in Year 10 or 11 before you can take part in the exchange.

Now 14 years old, Richard has been learning French since Year 3, dance and singing since he was 7, and studies drama at school. Currently he takes part in dance sessions at least four days a week, including ballet, hip hop, jazz and tap. Having already received a scholarship for the Hutchins School of Performing Arts in Dance he is planning to apply to audition for a Drama Scholarship later this year.

His teachers have been very impressed with his "energy and boundless enthusiasm" for performing arts and French. "Richard's zest for his craft and his commitment to his classes is always second to none. He has a natural

flair for performance and is a fine dancer and singer who always puts in 100%," said Michelle Williams, Richard's dance teacher from the House of Dance in Hobart.

During the exchange trip at the Lycee Racine in Paris, Richard will attend school and take part in performing arts classes with the other French students. "It will be great to go there and immerse myself in French culture and language, and being part of performing arts classes there as well is even better," said Richard. "It will be really cool to see what type of dancing they do there and how they work in their performing arts".

Richard has von Willebrand disorder but has never allowed it to stop him in his pursuit of his life plans. "I've lived life on the safe side, and don't do too much extreme stuff, but I say do what you want to do - unless it's really dangerous!". After he has finished school, he hopes to go to one of the leading educational institutes for performing arts in Australia, such as NIDA (National Institute of Dramatic Art) in Sydney or WAAPA (Western Australian



Academy for Performing Arts). His life goal? "I'd like to always be on the stage, dancing or singing. It would be a great experience to travel around the world performing, seeing new places - Australia, New York, London, everywhere!"

Winning the Vision and Leadership Award has helped him to make the next step in realising his plans. The Award will help to cover the cost of his airfares.

What message does he have for other young people with bleeding disorders? "Go for your dreams and do what you want to do." He felt that applying for the Awards was one way to achieve this and encouraged others to do the same: "The Awards help you follow your dreams, no matter what they are. They help you do what you want to do and help you get where you want to be. " H"

Richard Davidson-Lim on the stage

CALENDAR

Australasian HIV/AIDS Conference 2010

20 - 22 October 2010

Phone: 02 8204 0770

Fax: 02 9212 4670

email info@hivaidconference.com.au

www.hivaidconference.com.au

Haemophilia Awareness Week

10-16 October 2009

ph 03 9885 7800

fax 03 9885 1800

email hfaust@haemophilia.org.au

www.haemophilia.org.au

2011 Australia and New Zealand Haemophilia Conference

20 - 22 October 2011

Novotel, Sydney Olympic Park,
Sydney NSW

ph 03 9885 7800

fax 03 9885 1800

email hfaust@haemophilia.org.au

www.haemophilia.org.au

XXX International Congress of the World Federation of Hemophilia Paris, France 2012

www.wfh.org

XXXI International Congress of the World Federation of Hemophilia Melbourne, Australia 2014

www.wfh.org

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 who provide grants to HFA to support our programs:

Baxter

CSL Bioplasma



Wyeth



ashm

Australasian HIV/AIDS Conference 2010

21st Annual Conference of the Australasian Society for HIV Medicine
Sydney, 20 -22 October 2010

The Australasian HIV/AIDS Conference 2010 (22nd Annual Conference for the Australasian Society for HIV Medicine) to be held from 20 - 22 October 2010 at the Sydney Convention and Exhibition Centre, Sydney, New South Wales.

The Australasian HIV/AIDS Conference brings together the range of disciplines involved in HIV Management including Basic Science, Clinical Medicine, Community Programs, Education, Epidemiology, Nursing and Allied Health, Policy, Prevention, Primary Care, Public Health and Social Research.

The Conference is an opportunity to hear about the latest advances from leading local and international figures.

Register by Thursday 7 October. After 7 October a late registration fee of \$110 will apply to all registration types with the exception of day registrations.

For more information, visit the Conference web site : www.hivaidconference.com.au

WE WANT YOUR FEEDBACK!

HFA is committed to maintaining a high standard of service to the bleeding disorders community, but to do this we need your feedback on our programs and services.

You will notice that a survey form and a reply paid envelope have been included with this issue of *National Haemophilia*. Please take a moment to answer these quick questions and let us know how we can best provide services and be relevant to you and the bleeding disorders community now and in the future.



NATIONAL HAEMOPHILIA is a publication of Haemophilia Foundation Australia. Every effort is taken to ensure accurate and relevant content, however opinions expressed in NATIONAL HAEMOPHILIA do not necessarily reflect those of the Foundation or the editor, nor is any information intended to take the place of advice from a qualified medical practitioner or health professional. Haemophilia Foundation Australia does not endorse or assure the products, programs or services featured in NATIONAL HAEMOPHILIA and does not make specific recommendations for any products, programs or services. We welcome reproduction of articles or quotations from NATIONAL HAEMOPHILIA on the understanding that acknowledgement is made of NATIONAL HAEMOPHILIA as the source. Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health and Ageing which makes this publication possible.