National Haemophilia

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Congress Reports Inside

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The new National Blood Authority (NBA) contracts for the supply of recombinant and certain plasma-derived products took effect from 1 July 2006. These contracts provide products which are not produced in Australia, but are necessary for the treatment of people with haemophilia and other bleeding disorders.

NEW GOVERNMENT CONTRACTS FOR RECOMBINANT HAEMOPHILIA PRODUCTS

Background

A major improvement for the safety and supply of haemophilia products available in Australia occurred in 2004, when governments agreed to fund increased access to recombinant treatment products. This meant that all people with haemophilia could use recombinant treatment products regardless of blood borne viral status or age. This was important because it meant people could use a treatment product manufactured with little or no human material which reduced their risk of transmission of blood borne viruses or the theoretical risk of agents such as vCJD.

People with haemophilia A and von Willebrand disorder who require plasma-derived clotting factor concentrate will continue to have access to plasma-derived factor VIII (Biostate®) manufactured by CSL Bioplasma. Steps have been taken in Australia to increase the safety profile of the donor pool from which Biostate® is produced and in the manufacturing processes to enhance the safety of Biostate® for those using this product.

Products available

The new NBA contracts will enable people with haemophilia A to choose from two additional recombinant products. The NBA had a contract with Baxter to supply recombinant factor VIII Recombinate® from 2003-2006. The new contracts mean that haemophilia A patients can choose from three recombinant products now available;

- *Recombinate®* (Baxter Healthcare Australia Pty Ltd),
- *Advate®* (Baxter Healthcare Australia Pty Ltd), and
- *ReFacto®* (Wyeth Australia Pty Ltd).

Wyeth is also the only manufacturer worldwide of recombinant FIX, BeneFIX®, which is used by people with haemophilia B. MonoFIX®-VF which is manufactured by CSL Bioplasma is also available for the treatment of haemophilia B when plasma-derived factor IX is considered clinically more appropriate.

The NBA contract with Novo Nordisk Pharmaceuticals Pty Ltd provides for the supply of NovoSeven®, recombinant factor VIIa for the treatment of people with inhibitors to factor VIII and IX. Novo Nordisk is the only manufacturer worldwide of recombinant factor VIIa.

Plasma-derived factor XI and plasma-derived factor XIII are also imported under a separate agreement with CSL Limited.

In comment to HFA, NBA Deputy General Manager Peter DeGraaff said "The new contracts include features and provisions which will provide additional benefits to patients, clinicians and governments".

Recently the NBA conducted presentations for clinicians, Haemophilia Foundation Australia

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and State/Territory Haemophilia Foundation representatives and others on the new arrangements in Brisbane, Sydney, Canberra, Melbourne, Adelaide and Perth. At these presentations Mr DeGraaff outlined the new arrangements and answered questions on a range of issues. He emphasised that the NBA took full responsibility for managing the contracts with suppliers. "If clinicians, nurses and others have any problems with the supply of products they should be raised directly with the NBA which would then liaise with the supplier. This will enable clinicians and nurses to concentrate on working with their patients rather than having to deal with supply problems," said Mr DeGraaff.

The NBA will maintain an Issues Register for each contract, and will provide feedback to those who raised issues (if they wish) once the issues have been resolved with suppliers. More information is available on the NBA website at www.nba.gov.au, and feedback can be sent to dbp@nba.gov.au.

What to do now?

HFA recommends that people should consider their new treatment product options in consultation with their treating haemophilia specialist.

Important Message From HFA President Gavin Finkelstein

There are now several haemophilia treatment products available for people with haemophilia in Australia to choose from. Recombinant products are recommended as world best practice treatment for people with haemophilia. While some people use plasma-derived products for clinical reasons or personal choice most people with haemophilia switched from plasma-derived to recombinant clotting concentrates in 2004-2005 when increased government funding allowed wider access for everyone. This was a major step forward for Australians with haemophilia, and brought our community in line with other countries, some of which had made this decision many years earlier. It is important to remember that all plasma-derived and recombinant products registered for use in Australia meet Therapeutic Goods Administration standards for safety and efficacy.

A decision about which treatment product to use should be based on an informed decision based on good clinical advice as to what is best for each person. As treatment products may differ in the manufacturing process used, or in their packaging and administration, it is important that people make an informed decision about what is best for them, based on their medical history, in consultation with a specialist haemophilia clinician at a haemophilia centre.

It is also very important to have ongoing clinical support and monitoring to ensure that a good treatment plan is made, especially when bleeding frequency and treatment response changes, or other health issues occur.

Home therapy has changed our lives. It has given us independence and an ability to treat ourselves away from hospitals. We can lead normal lives without the fear of having a bleed and not being able to get treatment. We can travel, or go to school or work and participate in a range of recreation and community activities – our bleeding disorder doesn't need to rule our lives as it might have done in the past – it is just a part of who we are.

We need to take responsibility for our care and treatment. We might consider we have a right to high quality treatment and care in Australia – we are fortunate that we live in a country with high standards of health care. My recent attendance at the WFH Congress and WFH General Assembly in May served as a reminder for me that care and treatment for bleeding disorders is very limited in many countries of the world. HFA has made a commitment to do its share to improve diagnosis, care and treatment in countries where care and treatment is patchy or unavailable.

Both plasma-derived and recombinant treatment products for haemophilia and von Willebrand disorder are expensive, and they are very valuable health resources. The increased government funding provided to allow increased access to recombinant clotting factors and the work of the National Blood Authority to manage demand and supply gives us comfort that we should not suffer from treatment product shortages in Australia as we have done in the past. We are fortunate that everyone who requires treatment in Australia can receive it. HFA has worked with other stakeholders towards sound guidelines about treatment. It is true that supply should be less of a problem now than in the past. This does not mean we have unlimited access to treatment. Our treatment product is expensive and the amount of treatment product used in Australia increases each year. There are some people who argue that the bleeding disorders' community has an unfair share of the health dollar in Australia. Governments are worried about the increasing costs. There needs to be an assurance that the costs are necessary and managed well. The new contracts are aimed at achieving cost benefits, better demand and supply planning and management, and we hope the benefits will come through to patients, haemophilia centres and to governments in various ways.

HFA will work with other stakeholders, including the NBA, the Australian Haemophilia Centre Directors' Organisation, haemophilia centre staff and State/Territory Haemophilia Foundations so that we have a good understanding of the needs of the bleeding disorders' community, adequate supplies, and access to treatment product where it is needed. Cost and cost effectiveness is important, but people need the treatment products they require, in the quantity they require, to achieve the best health for them. We need safe and effective treatments that meet best practice standards. We will play our part to make sure best practice, relevant and accurate data and evidence is reflected in our treatment and care. HFA will undertake this on your behalf so you can concentrate on your health.

We need to be personally responsible and accountable as well. We must ensure we use product appropriately - that we do not waste and that we are accountable – that we treat with what we need, and that

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we work with the people providing our care and treatment to make sure our treatment plan is right for us.

What can you do to be responsible and accountable? Make sure you have regular reviews and assessments at your haemophilia centre, report changes in bleeding frequency and/or your treatment response. Don't just "do your own thing". We have all been educated about how to take responsibility for our care and treatment - we have learned "that if in doubt, we should treat". We should do that, but we also need to discuss changes or concerns with our treating health professionals and make sure our individual treatment plan is the best one for us. If you will be switching products I suggest this is part of a planned process so you do not waste the stores you have at home and that you discuss an appropriate changeover plan with your haemophilia nurse or your doctor.

Recombinant Products – Manufacturing Process

The following material is drawn from a range of sources including Medical and Scientific Advisory Council (MASAC) of the USA National Hemophilia Foundation and United Kingdom Haemophilia Centre Directors' Organisation (UKHCDO) on the selection and use of therapeutic products to treat haemophilia and was published in the March 2004 edition of *National Haemophilia*.

The gene for factor VIII was cloned in 1984 and recombinant factor VIII has been produced since the late 1980's. It has been used in Australia since 1994 for the treatment of children with haemophilia. Recombinant factor IX has been on the market since 1997 and available in most States/Territories in Australia, except South Australia, since 2001.

Manufacturing methods for rFVIII have changed since the first products were produced and whilst all have an excellent safety record, they have varying amounts of human or animal material in the process or final product, and therefore different risk profiles – even if the differences are minimal.

First generation products contain animal and/or human plasma-derived proteins in the cell culture medium and human albumin is added to stabilise the final formulation. Second generation products contain animal or human plasma proteins in the medium but are stabilised with sugar instead of human albumin. Third generation products do not contain any animal or human plasma-derived proteins in the culture medium or in the final vial.

There are now three recombinant factor VIII products, and recombinant factor IX BeneFIX® for the treatment of haemophilia B available in Australia:

- a first generation rFVIII (Recombinate®, manufactured by Baxter),
- a second generation rFVIII product (ReFacto®, manufactured by Wyeth),
- a third generation rFVIII (Advate®, manufactured by Baxter), and
- a third generation rFIX product (BeneFIX®, manufactured by Wyeth).

(Recombinant factor VIIa – NovoSeven®, manufactured by Novo Nordisk, is used in Australia for the treatment of inhibitors to factor VIII and factor IX.)

Recombinant Products Now Available

rFVIII Recombinate® (Baxter)

1000 IU

500 IU

250 IU

store at room temperature (up to 30˚C)

rFVIII Advate® (Baxter)

1500 IU

1000 IU

500 IU

250 IU

store at 2-8˚C

rFVIII ReFacto® (Wyeth)

2000 IU

1000 IU

500 IU

250 IU

store at 2-8˚C

rFIX BeneFIX® (Wyeth)

1000 IU

500 IU

250 IU

store at 2-8˚C

rFVIIa NovoSeven® (Novo Nordisk)

1.2mg

2.4mg

4.8mg

store at 2-8˚C

POSITIVELY NEGATIVE

Neil Boal

Neil Boal is a past President of Haemophilia Foundation Victoria, and former member of the HFA Council.

Apart from not having hep C anymore, I don't seem to have any nausea and my energy and motivation levels are through the roof, well for me anyway.

Ohmigosh! (ó-my-gosh) -interj.
1. Used to express surprise, amazement or astonishment.

Ohmigosh! I can't believe how good I feel. I'm a new person. Ok, I had to get that out first, but let's get to the reason. Fanfare please… I am now hep C negative! Man it feels good to say that. Obviously this is a successful outcome of finishing my hep C treatment program, but I'm getting a bit ahead of myself so let's rewind about 12 months.

As with many of you reading this, life had been pretty tough. Haemophilia, arthritis, HIV and hep C, and dealing with normal day-to-day pressures were getting pretty hard to deal with. I was constantly fatigued, in pain, suffering nausea and my mood was pretty flat. The thing is I could never really work out what was actually contributing to all of these problems (apart from bleeds and arthritis). Was it the gazillion medications I take for HIV? Or perhaps the HIV itself? Was hepatitis C the culprit, after all I've had it since the mid 70's? Well we really know it's a combination of all these things. But what impact does each illness have?

I don't need to tell you about your bleeding problems and the impact treatment has on rectifying (or preventing) these. HIV is a brutal, efficient killer but can be reasonably symptom free until it advances. Thankfully we now have lots of medicines to help control this monster, but they can create major problems of their own, at least until we find ones that suit our systems. Hep C is a lurker, slowly going about its business over a long time with barely a whimper.

I always put more blame on HIV and (to a lesser extent) haemophilia than hep C for my well-being. Besides there wasn't much we could do about the hepatitis any way. Sure, interferon came along but was such a drawn out treatment program with awful side-effects and had a hopeless success rate that it had no appeal to me at all. When the current interferon and ribavirin combination began and the success rates started to climb, my ears began to prick up. However it was still encumbered with some off-putting side effects and I'm sure you've read about those.

It took some personal circumstances to change and a lot of soul searching to finally decide to embark on this treatment journey. I had read as much as I could about the treatment, its potential problems and personal stories from people who had been there before me. Just as important was Julie's input. We both decided that the time was right to give this thing my best shot.

Now, fast forward to today. Reflecting on my treatment period of 48 weeks, I can't say I enjoyed it. I had a few side effects but none were too bad for me to stop. I was more tired than usual and my motivation was next to nil. I must add I felt a little worse in the last eight weeks but I was nearly there. My mood had more ups and downs than the Alfred's lifts, but nothing scary and my hair did thin out a bit. Some of my blood counts went a bit haywire but didn't amount to much.

Now, some four weeks on, everything has returned to normal. Actually that's not true, because I'm feeling better than I have since the early 90's, but you know what I mean. Apart from not having hep C anymore, I don't seem to have any nausea and my energy and motivation levels are through the roof, well for me anyway.

There is a downside and that is my joints are sore because I'm out there doing all of these odd jobs that have been put off for such a long time! But that's a pretty good trade-off. I think I'm just making the most of it in case it doesn't last, that's the thing; it could return in the next six months so that's the next hurdle. Let's enjoy it for now.

If I could offer advice it would be to involve your family so they can understand how hard this can potentially be - support is as important as the treatment itself. Also, make sure you are ready. It's hard work and you need to give yourself the best possible chance of a positive, err, negative result. What could be a better reason?

What Do You Have To Tell Your Dentist And Doctor

Piergiorgio Moro

The following article was published in Good Liver, Autumn 2006, the newsletter of the Hepatitis C Council of Victoria.

One of the common questions we are asked at the Hepatitis C Council of Victoria is whether people have to disclose their hepatitis C status to doctors, nurses and dentists. The short answer to the question is no. There are very few instances where legally a person has to disclose their status.[1]

In terms of transmission of the virus and the risk of infecting other people, all doctors, dentists and other health workers must follow standard infection control guidelines all the time. This means that all blood and bodily fluids are treated as infectious, all the time. Therefore, for someone who has hepatitis C, no extra precautions are required, as standard precautions are sufficient to prevent the spread of the hepatitis C virus. These infection control guidelines have been developed over time to give the best protection from cross contamination to both the health practitioner and the patient.

Of course, in terms of best practice health care, it would make sense if the medical practitioner who is treating you has a complete knowledge of your health. They could then assess you fully in terms of what symptoms you have; what the underlying causes of these may be; the interaction between various illnesses that you may have, and potential side effects and/or unintended effects of prescribed drugs.

Take for example the potential effect that hepatitis C may have on your oral health. For many people, hepatitis C leads to the absence of saliva resulting in a dry mouth, a condition known as xerostomia. As saliva is integral to oral good health, its absence can lead to an increase in sore oral tissues, halitosis, dental decay and tooth sensitivity.

But despite these good reasons, the unfortunate reality is that many people with hepatitis C still encounter discriminatory attitudes and practices from health practitioners.[2] Many people do not feel comfortable disclosing their hepatitis C status to a health worker, especially in an initial visit when they are unsure what response they will be faced with.

At the Council we hear of many cases of people being asked how they got hepatitis C; of having to face derogatory and/or paternalistic comments about past, current or assumed drug injecting behaviour; being told that extra precautions/ routines were needed for them; or even that people like them were not welcomed in that health practice.

Such behaviour is not only unacceptable, but in most cases would be contrary to anti-discrimination legislation. If you decide to tell your medical practitioner that you have hepatitis C, you are under no obligation (and should not really be asked) to answer questions on 'how you got it'. There are no reasons for you to be treated with any extra precautions, and you have the right to be treated exactly the same as everyone else.

Access to the highest quality health care is not a privilege, it is a right that all people living in Australia should be able to enjoy without fear of rejection and/or discrimination.

While the majority of doctors, dentists, nurses and health workers are professional and non-judgemental in their work, there are unfortunately some who do not meet these standards.

If, as a patient, you feel that you are being, or have been, subjected to discriminatory treatment, do not remain silent about it. Let the medical practitioner know that you do not think what they are doing is correct. You can change to another practitioner or you can take action by complaining to the appropriate Registration Board, eg the Dental Practice Board of Victoria and/or the Equal Opportunity Commission.

References:

1.The major areas/instances where people with hepatitis C have to disclose their status include: if they want to donate blood, if they want to join the army and/or the secret service, if they are health workers performing invasive procedures, and if they are applying for new health and/or life insurance policies.

2.i)Anti-Discrimination Board of New South Wales. C-Change: Report of the enquiry into hepatitis C related discrimination, Sydney, 2001.

ii) Unpublished PhD thesis – Jacqueline Richmond. Is there an association between health professionals' hepatitis C knowledge and attitudes and the care they provide to people with hepatitis C? School of Nursing, Faculty of Medicine, Dentistry and Health Sciences – the University of Melbourne, 2005.

5th Australasian Viral Hepatitis Conference

Dr Graeme Macdonald

Dr Graeme Macdonald was Conference Convenor for the 5th Australasian Viral Hepatitis Conference. He is based at the University of Queensland, School of Medicine. Sharon Caris, HFA Executive Director, was a member of the Conference Program Committee.

(The following article was published in ASHM News, Volume 7 No.3, May 2006)

The 5th Australasian Viral Hepatitis Conference was held in Sydney from 20-22 February 2006. The conference theme was "Increasing Access". This had a broad focus including: increasing access to resources to prevent transmission and facilitate diagnosis; increasing access to antiviral therapies and other management options; increasing access to the data resources for workforce development and to the means to address discrimination and stigmatisation; and promoting the access and communication between researchers, affected communities and policy makers. In response to the importance of hepatitis B in the region, the name of the conference was changed and a deliberate attempt made to increase the content related to hepatitis B.

The invited plenary speakers included four international and eight national speakers. The conference was opened by Hon Tony Abbott, the Minister for Health and Ageing, who announced the removal of the requirement for liver biopsy to qualify for government-funded treatment of hepatitis C, effective from 1 April 2006. This change will result in a significant increase in access to interferon-based therapies for hepatitis C, particularly in those with mild disease histologically.

Many attendees are used to going to discipline-specific meetings. The interaction between people with different backgrounds is one of the strengths of the Viral Hepatitis Conference. This has the potential to cause contention when attendees feel that their particular area of interest is inadequately represented. However, the international invited speakers stated that they found exposure to a range of disciplines stimulating and indicated that there is no similar conference in either Europe or North America. One stressed that the presentations from affected communities had refocused their commitment to research. There were a number of other highlights during the conference, including therapies under development (such as pre-clinical development, those undergoing clinical evaluation and vaccine approaches); the management of viral hepatitis in prisons; the role of nurse-led and shared models of care; and indigenous communities' responses.

In total, 146 abstracts were submitted, with the majority being accepted for oral presentation and 47 as posters. The oral presentations were across all six of the conference streams and consistently of a high standard. An oral poster session that briefly reviewed 15 posters was particularly popular.

In the final summation of the conference a plea was made to establish a national body with a similar but distinct structure to Australasian Society for HIV Medicine (ASHM), to focus on viral hepatitis. ASHM has been a tremendous force for viral hepatitis in Australia, but for a number of us our primary expertise is in viral hepatitis, not HIV/AIDS. Although the issues related to hepatitis B and C are in some ways similar to those facing HIV, there are distinct challenges. I hope this call for a distinct Australian hepatitis body leads to discussion and correspondence in the publications of ASHM, Gastroenterological Society of Australia, Australian Hepatitis Council and other interested bodies.

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Short Course In HIV Medicine For Community

Leola Farnell

Leola Farnell is Haemophilia Social Worker at the Royal Prince Alfred Hospital, Sydney. She attended the Short Course in HIV Medicine for Community, held in Sydney on 2-3 March 2006, and her overview follows.

The AIDS Treatment Project Australia and the Australasian Society for HIV Medicine collaborated to produce a very informative and valuable two-day course that I was fortunate to have been able to attend on behalf of HFA. About 50 HIV workers from around Australia came together to hear speakers talk on a range of HIV related issues from a variety of different perspectives. The program moved steadily over the two days and provided a good mix of speakers from all aspects of HIV/AIDS work, some group work and feedback from the client group. I will endeavour to summarise the information that would be most interesting and relevant to the haemophilia community.

To start with we were given an overview or refresher of the HIV virus transmission and reproduction path and an epidemiological overview of HIV in Australia by Fraser Drummond who is the Clinical Project Leader for the National Centre in HIV Epidemiology and Clinical Research. The virus progression was re-visited many times throughout the course and by the end we all had a good grasp of how it all works.

'HIV is transmitted through sexual contact, blood to blood contact and mother-to-child transmission. Without treatment, most infected individuals develop severe immune deficiency within ten years. Combination therapy has transformed the course of the disease, extending the life expectancy of infected individuals by many years.' (HIV/Viral hepatitis: a guide for primary care, Dore, G, et al 2004)

It is still unknown as to how HIV was first transmitted to the human population, but the common belief is still that it originated from primates in Africa.

A brief description of the viral path as seen in the diagram provided: the HIV virus consists of two encased copies of the single stranded ribonucleic acid (RNA) virus and other viral proteins that attach to the preferred CD4 Lymphocyte cell at two receptor sites, CD4 and CCR5; the membranes of the virus and cell then fuse together allowing the virus to enter the cell. The single stranded RNA is then converted into double stranded DNA by the reverse transcriptase enzyme and then combined with the cell's own DNA by the integrase enzyme. Long chains of proteins are made when the infected cell divides and the viral DNA is interpreted. Sets of viral protein chains come together and the young virus then pushes out of the cell, taking some cell membrane with it. Immature virus breaks free of the infected cell and the virus starts a process of maturation. Hopefully that makes sense!

The good news is that the incidence of HIV transmission and diagnosis has remained at a consistently low rate since the late 1990's as a result of successful educational campaigns and better management of blood products. The incidence of progression to full blown AIDS has also remained low with the introduction of better products and more effective combinations of anti-retroviral (ARV)medication. Fraser also spoke about the gradual development and advances in drug treatment and how these drug classes impact on the replication cycle. One issue for prescribers is the problem of compliance with medications; doctors expect or require 95% adherence to a drug regime for it to work well, as anything under this reduces the efficacy and leads to drug resistance. He also informed us that new drugs are being designed in such a way that resistance is difficult.

Phillip Cummingham from the NSW State Reference Laboratory for HIV/AIDS, St Vincent's Hospital Sydney, spoke about the various tests being used in laboratories to diagnose HIV infection stages. The current tests are able to more accurately determine what stage the virus is at, monitor anti-retroviral therapies and diagnose opportunistic infections. The main screening test used is called ELISA (enzyme linked immunosorbent assay) which uses a tool called the Western Blot that measures the viral proteins in a sample to detect HIV antibodies and HIV antigen activity. These tests have also proved effective for monitoring and adjusting a patient's medication to maintain CD4 counts and viral loads at normal levels, and for patients who are resistant to ARV.

Next up we took a change of pace with our own HIV Psychiatrist from RPAH in Sydney, Dr Melissa Corr, who spoke on the importance of pre and post-test counselling as a means of reducing the distress of diagnosis. People being diagnosed with HIV suffer the symptoms associated with normal grief reactions, ie anxiety, sadness, guilt, anger, denial and insomnia. How someone adjusts to a diagnosis of HIV as with any other potentially life threatening illness

depends on a number of factors, ie past psych history, social supports, or whether they use denial as their only defence. Some of the most common adjustment disorders to monitor are depression, anxiety and behavioural changes, like substance abuse, risk taking behaviour and suicide attempts. Dr Corr did point out that some behavioural change can be a result of the progression of HIV, ie mania, psychosis, delirium, and not psychological as such. She also spoke about the diagnosis and management of HIV dementia.

The introduction and evolution of Highly Active Anti-Retroviral Therapy (HAART) has had an enormous impact on the quality of life of people living with HIV/AIDS. Some of the benefits listed by Russell Levy, Pharmacist at St Vincent's Hospital are a reduction in disease progression, reduction in AIDS diagnosis, reduction in opportunistic infections, reductions in hospitalisations, reduction in AIDS related deaths and previously ill people returning to work. The main development has been reformulating old drugs so they are easier to adhere to, less toxic and more readily available. These new formulations include Lopinavir/ Ritonavir which among other things now has no food requirements, a reduced pill burden and a better shelf life. The other is Saquinavir which has gone from being a dose of six 200mg tablets three times a day down to two 500mg twice a day with ritonavir, and still best with food. The other developments have been in combination products where you can get two drugs of the same family in one tablet. The emerging issues are virological failure, long-term side effects and drug interactions.

Jo Watson from NAPWA, (National Association for People Living with HIV/AIDS) gave an interesting talk about new drugs and how NAPWA is advocating for better anti-retroviral products and faster access to new products. The review of anti-retrovirals began in 1998 as new drugs were needed to replace ones that people had become resistant to. Since 1998 the pace of drug development has been quite low, but more information is now available on which ARV's work best. Jo lists the reasons why drugs didn't work were that they were not potent enough, were too demanding dose-wise, or were fad drugs. There are 21 ARV drugs available today in Australia. The focus of drug development as mentioned earlier is for fewer pills, less pressure on organs, well tolerated, different resistance profile, and that they attack a variety of targets. Up until about 18 months ago the pace of new drug development had been slow and disappointing. Recently production has picked up and there is the potential for 30 anti-retroviral drugs in six classes (targets) within the next five years; there are 23+ drugs in clinical trials at present and NAPWA has identified 11 as being promising. It is anticipated that the next generation of protease inhibitors will have properties of durability and safety that the current ones do not. Unfortunately it takes some time for drugs to move through the approval process and NAPWA is involved in the regulatory, advocacy and policy process required to remove barriers to access.

David Baker, a high HIV caseload GP, spoke about the latest research findings into the possibility of treatment interruptions or 'drug holidays' as a future treatment option. Unfortunately the results were not encouraging; he started the talk with the answer, which is 'don't without a good reason!' or 'preferably within a study if available'. The SMART study was designed to compare two groups, both starting with a viral load >350 where one is on ART consistently and the other defers ART until they have a viral load below 250, then they begin episodic treatment. It was found that the drug conservation group had an increased risk of progression to AIDS, including death, serious disease progression events or major cardiovascular, renal and liver events. The study concluded that treatment interruptions based on CD4+ count levels was inferior to continuous treatment. He did add to this that most patients do stop anti-retroviral medication at some stage for one reason or other and that is why they need to understand the consequences of this.

Lastly, Peter Canavan from NAPWA highlighted some of the findings from a survey on the experiences of people living with HIV/AIDS (PLWHA) in Australia. As with haemophilia one of the emerging issues is older people with HIV and the issues that they face, ie other health problems on top of HIV, fewer treatment options and increasing resistance, financial difficulties, access to services and social isolation. Living longer and being on treatment longer brought up issues related to quality of life and the study was able to analyse the factors that related to the burden of illness. Ultimately the complexities of living with a condition like HIV will increase as time goes by. Peter talked about some of the changes that have occurred over time that affect the burden of the illness as being improvements in health and treatments, changing needs of PLWHA as identified through service access and involvement, increase in PLWHA moving from part-time back to full-time employment and a slight improvement in the stigma and discrimination experienced by PLWHA.

The short course was finished with a panel discussion with PLWHA from a variety of different backgrounds who were able to give their experiences of how they came to have HIV and how it has affected their lives. It was a very enlightening and fascinating discussion and a great way to end the course.

A Winning Coalition

Sharon Caris

World Federation of Hemophilia (WFH) President, Mark Skinner's opening plenary address at the XXVII International Congress of the WFH in Vancouver in May described how the WFH vision for improvement could be achieved through a winning coalition! Sharon Caris, HFA Executive Director reports on his presentation below.

In Mark Skinner's presentation he noted that 70% of the world's bleeding disorder population is not diagnosed and 75% is not treated. Many countries lack infrastructure, training and education, haemophilia is not a priority with governments, and treatment is unaffordable. As a result, many die in childhood or live with chronic disability and impaired quality of life. Since the Bangkok Congress in 2004, however, a 14% increase in the number of people diagnosed had occurred.

WFH works to improve and sustain care for people around the world. He said to achieve its objectives WFH required a winning coalition with:

- Patients and their families
- Health care professionals – doctors nurses, social workers, orthopaedic surgeons, physiotherapists, dentists, laboratory technicians and blood services
- Governments and health ministries
- Vital strategic partners
- Regulators
- Industry

What Is Treatment For All?

- Safe, effective treatment products are available for all people with inherited bleeding disorders
- Proper diagnosis, management and care by a multidisciplinary team of trained specialists
- Expanding services beyond haemophilia to those with von Willebrand disorder, rare factor deficiencies and inherited platelet disorders

This plan has four strategic cornerstones:

- Improving standards of treatment
- Teaching, training, education and information
- Monitoring advocacy and research to improve treatment
- Resource management

The vision of treatment for all is put into operation in the plan through strategic themes:

- Improving treatment in emerging countries
- Ensuring continued development and sustained treatment where it is already well established
- Enhancing access to treatment for von Willebrand disorder, rare factor deficiencies and inherited platelet disorders
- Sharing knowledge and building capacity through information exchange and training
- Promoting access to safe and improved treatment and cure-related research
- Expanding and diversifying our financial base
- Enhancing and adapting the WFH organisational structure to meet the challenges ahead

A commitment to core activities is vitally important to achieving long term success through;

- NMO Skills Training
- Organisation and Centre Twinning
- Humanitarian aid
- Medical training and IHTC fellowships
- Multidisciplinary workshops
- Laboratory quality assurance scheme

The WFH Global Alliance for Progress (GAP) Program launched in 2003 aims to close the gap in care between developed and developing countries. Already since then, the GAP program has seen six Agreements signed with the governments of Armenia, Azerbajan, Egypt, Georgia, Jordan and Thailand. That means haemophilia care has been placed on the national health care agenda at the highest level and obtained commitments to funding. Further countries may soon take this step.

Treatment for all requires an adequate supply of safe affordable factor replacement therapy. Recently treatment access has increased in China, Egypt, Russia, Georgia, Mexico, Saudi Arabia and Thailand as a result of these programs and activities. But the real key is sustainability – these gains need be sustained over time.

WFH recognises that not all countries will be able to purchase clotting factor concentrates and other initiatives to assist are under way. For example, WFH has published Treatment Guidelines for the Management of Haemophilia which is a useful tool for clinicians in all countries to better understand optimal use of treatment resources.

It is important to identify patients who need treatment and care. By reaching out to them, WFH will also strengthen its numbers and broaden its base of support.

Humanitarian aid is another important activity to provide treatment product for medical emergencies in countries where treatment product is unavailable or limited. This also provides incentive for sustainable care later. However, the amount of product available to WFH for its humanitarian aid program varies from year to year. Mr Skinner noted the generosity of manufacturers over the years and emphasised the need to stabilise the predictability of donations, and to develop effective ways of recovering and using surplus supplies of plasma.

Twin track pricing is another strategic objective to allow emerging countries access to affordable products.

Sustaining treatment where it is well established is also important – the health care environment in established countries is very competitive and there are many demands on public health funding. Where treatment is already established WFH wants to ensure continued development and that the level of care is sustained. It is important that comprehensive care networks are maintained in established countries so they can maintain services and care, and in turn engage with twinning and fellowship training programs for the benefit of the worldwide community.

Meeting unmet treatment need is also very important in the strategic vision of WFH. Von Willebrand disorder is frequently undiagnosed and/or misdiagnosed. It is important to identify patients who need treatment and care. By reaching out to them, WFH will also strengthen its numbers and broaden its base of support.

WFH views both recombinant and plasma derived products as equally important to the global bleeding disorders' community. Both now have a robust safety record and the supply of either alone does not meet current and future needs. The wide range of products, their cost and the differing economic capacity of the countries means that different product selection decisions will be appropriate for any given market or individual patient. Maintaining such diversity provides valuable assurance that our community will be prepared for the future.

Historically we have focussed on pathogen risks such as HIV, hepatitis C and vCJD. In the future we will define risk more broadly. The development of an inhibitor is the most significant adverse event associated with treatment and a problem faced by 20-30% of patients with severe haemophilia A. We must have global collaboration to achieve a better understanding of the incidence of inhibitor development, the risk factors for developing an inhibitor and the best strategies to treat and manage inhibitors. A global approach is also required to achieve a cure for haemophilia. We need to support research that improves treatment options, increases half life of treatment products and leads to a cure.

To expand and diversify the WFH financial base Mr Skinner said that WFH needed to work with existing corporate donors and partners, and develop new funding sources, beyond pharmaceutical companies and expand affiliated organisations and connections and ensure WFH revenues and staffing levels are sufficient to meet planned expenditure.

In order to enhance and adapt WFH structure to meet its ongoing and future need it would review its constitution and policies, strengthen internal communication, encourage organisation wide succession planning and invest in professional staff. A new Medical Advisory Board has been established by WFH.

In closing Mark Skinner said that WFH was well positioned to achieve its objectives because it had the winning coalition – it has the commitment and dedication of National Member Organisations, WFH volunteers and staff, governments committed to building national haemophilia programs, and corporate partners and supporters.

XXVII International Congress Of The World Federation Of Hemophilia, Vancouver

The XXVII International Congress of the World Federation of Hemophilia was held in Vancouver, Canada, in May 2006. Australia was well represented, including members of Executive Board, health professionals' groups and State/Territory Haemophilia Foundations.

Hemophilia 2006

Peter Fogarty, President, Haemophilia Foundation Queensland

It is hard to know where to start with a report on such a massive event as Hemophilia 2006. 4,000+ delegates from over 109 countries made it the largest world haemophilia congress to date. It is clear that many of the central themes that have run though the years continue to be strong, however many new themes are emerging at the international level that make the experience even more worthwhile.

The conference proper is run from 9am to 6pm each day, but additional satellite symposia made it possible to be in lectures and presentations constantly from 7am till 6pm. I managed 11-hour days for the first few days, but it is very draining and eventually the information was going in one ear and out the other.

It was clear from the outset this year that inhibitors are the source of much investigation in the scientific world at the moment. Many lectures revolved around the genetics of inhibitors and what environmental factors may be contributors to the development of inhibitors. A Patient's Story, presented by 22-year-old Richard Pezzillo in one of the satellite sessions was an emotional high point, as Richard shared his personal journey of inhibitors and his, so far, unsuccessful journey through immune tolerance.

The current research into inhibitors is focusing on the multi-faceted factors, which seem to give rise to their development. A large portion of inhibitor development lies with the nature of the genetic mutation that causes the haemophilia, however there is still conflicting information on the role of different factors on inhibitor development.

One of the other strong themes running through the congress was National Member Organisation (NMO) training and capacity building. Presentations on new and novel ways of engaging youth, fundraising, effective political lobbying and general capacity building for NMOs were available on most days, and I availed myself of these sessions wherever possible. There is no need to 're-invent the wheel' and the vast range of talent in the global community ensures that there is almost certainly someone, somewhere, who has already dealt with a given issue. The theme amongst developed nations, such as Australia, is certainly one of flagging community involvement, as people view the fight as having been won, since the provision of recombinant products for haemophilia patients. This is, of course, far from the truth, and the level of vigilance and dedication is required now as much as ever before as we face the issues of hepatitis C recompense, the ongoing survival of the multi-disciplinary comprehensive care program we take for granted now, and many other issues. Of course, once we look outwards from our own local situation, we are faced with the fact that 75% of the world's haemophilia patients are yet to be diagnosed and the current World Federation of Hemophilia mantra of Treatment for all is something that we must all help the community strive towards by doing whatever we can at the local, national and international level.

Congress Overview

Liz Jarvis, Haemophilia Nurse, The Canberra Hospital

Due to generous financial assistance from HFA and HFACT, I was recently able to attend the XXVII International Congress of the World Federation of Hemophilia, held in Vancouver.

Vancouver is a spectacularly beautiful city, bordered to the north by snow-clad mountains, to the west by the Pacific Ocean and to the south by the USA. With a population of just over 2 million it is the largest city in British Columbia, and the third largest city in Canada. It enjoys a mild climate with temperatures rarely going above 25 in Summer or below 5 in Winter. The only drawback is the rain, of which we copped our share, but the lushness of the gardens compensated for that. It's obviously the perfect weather for rhododendrons as they were in flower everywhere I looked. I found the Canadians to be friendly and relaxed, and with daylight lasting until 10pm and most shops open until 9pm every day, it was great to just wander the streets in the evening and enjoy the atmosphere.

The conference was held at the

Hemophilia 2006
World Congress, Vancouver, Canada
May 21 to 25, 2006

Vancouver Exhibition and Convention Centre which is located right on the waterfront in downtown Vancouver, and was attended by 4,000 delegates from over 100 countries.

The first day was divided into workshops for the various health professionals' groups, and nurses had the choice of attending either beginning or advanced programs. I chose the advanced program, which covered some very interesting topics. Two UK nurses spoke about the development of nurse-led haemophilia clinics, with one describing the course she had completed which enabled her to prescribe medications and the impact of that on haemophilia care. Other topics covered included an overview of rare bleeding disorders (including a case-study of a patient with factor XIII deficiency), severe haemophilia and ageing, acquired haemophilia, and an unusual case history of a family with both factor VIII and factor IX deficiency. Educating young people with bleeding disorders about nutrition, exercise and sport was also discussed with the worrying increase in childhood obesity.

That evening we were officially welcomed to the conference and Vancouver and were entertained by a Scottish Highland band and native North American dancing. The conference began in earnest the following day consisting of four full days of meetings, with topics of interest to doctors, nurses, counsellors, physios, dentists and scientists working in the field of haemophilia, as well as to people with haemophilia and their families.

The theme of this year's conference was Treatment for all; a vision for the future. Mark Skinner, President of the World Federation of Hemophilia, spoke passionately about WFH's new strategic plan, which embraces the vision of treatment for all, regardless of where they live in the world. Currently 75% of people with bleeding disorders' worldwide receive either inadequate or no treatment. WFH's mission is to improve treatment where it is limited or non-existent, while sustaining the many gains that have already been made. These include proper diagnosis, management and care by a multi-disciplined team of trained specialists; and expanding services beyond haemophilia to those with von Willebrand Disorder, rare factor deficiencies and inherited platelet disorders.

The conference contained many highlights, including the opportunity to meet other haemophilia nurses and learn more about how things are done in larger centres. One session of particular interest to me dealt with the transition of adolescents from paediatric to adult care. An American nurse described an education program she had developed to facilitate the process of adolescent boys taking more responsibility for their treatment and health. The program encouraged the boys to be thinking about suitable sport and career choices, girlfriends and genetic counselling issues, as well as taking responsibility for practical things like ordering their own factor and supplies. There were some really good ideas raised, and I plan to modify the program for our own boys in the ACT.

Prophylaxis

HM Van Den Berg, A Dunn, K Fischer and VS Blanchette

Prophylaxis is defined as primary (started before the onset of joint damage) or secondary (started after the onset of joint damage). The aim of primary prophylaxis is to prevent recurrent bleeding into joints and the development of chronic arthropathy in later life. When started early, and at most after two joint bleeds, the result is predictably excellent if there is compliance with the primary prophylaxis regimen. In order to decrease the need for central venous access devices to assure reliable venous access, a number of centres start primary prophylaxis with once weekly infusions with dose-escalation based on frequency of joint bleeding. A major unanswered question is whether primary prophylaxis can be safely discontinued in adolescents/young adults and if so, when? A promising predictor for the milder bleeding phenotype in persons with severe haemophilia is a later onset of joint bleeding. Once joint damage has occurred as a result of recurrent bleeding, secondary prophylaxis can only retard, but not prevent, ongoing joint damage. Other strategies to decrease recurrent bleeding from target joints include surgical synovectomy (ideally preformed using an arthroscopic technique), radionuclide synovectomy and chemical synovectomy. These interventions have a very good outcome when performed by an experienced team. Efforts should now focus on making more available the proven benefits of primary prophylaxis (improved quality of life and better musculoskeletal outcomes) to a greater number of persons with haemophilia worldwide. This aim will be facilitated by promoting high quality prospective studies that are designed to address currently unanswered questions about prophylaxis such as: optimal intensity of primary prophylaxis (dose and frequency), discontinuation of primary prophylaxis and the potential impact of primary prophylaxis on factor inhibitor development and intracranial haemorrhage in very young boys with severe haemophilia.

Haemophilia And Ageing

A Street, K Hill, B Sussex, M Warner and M-F Scully

Men with haemophilia have not only had the challenges of living with HIV and/or HCV infection and premature arthritis as complications of their disorder, but they also confront the other ails of aging. These include genitourinary problems such as prostatic hypertrophy, prostatic cancer and renal stone disease, and arterial disease for which

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haemophilia is not protective. Progressive arthritis and declining fitness may lead to loss of independence which causes great concern. Associated with the physical aspects of ageing, many patients also suffer from psychological symptoms which may be precipitated by changes in work such as early retirement and altered family dynamics. Many older men with haemophilia have never consulted primary care physicians because of the rarity and complexity of their disorder. Haemophilia centre staff often assume responsibility for the identification and management of all health problems of their patients. Even when other clinicians are involved, patients require their centre's involvement in the investigation and support of many procedures such as coronary artery surgery and urological surgery. This session addressed falls in the older man with haemophilia, their causes and consequences and cardiovascular problems in particular. Very little literature has been published about these common problems. We need to be aware of the ageing issues in haemophilia and develop "wellness" programs which are directed to the early identification of disease as well as preventative strategies to reduce the physical and psychological impacts of ageing.

von Willebrand disease: Clinical Management

AB Federici, G Castaman, A Thompson and E Berntorp

The aim of treatment of von Willebrand's disease (vWD) is to correct the dual defect of haemostasis, ie the abnormal platelet adhesion due to reduced and/or dysfunctional von Willebrand factor (vWF) and the abnormal coagulation expressed by low levels of factor VIII (FVIII). Desmopressin (DDAVP) is the treatment of choice for type 1 vWD because it can induce the release of normal vWF from cellular compartments. Prospective studies on biological response versus clinical efficacy of DDAVP in vWD type 1 and 2 are in progress to further explore its benefits and limits as therapeutic option. In type 3 and in severe forms of type 1 and 2 vWD, DDAVP is not effective and for these patients plasma virally inactivated concentrates containing vWF and FVIII are the mainstay of treatment. Several intermediate- and high-purity vWF/FVIII concentrates are available and have been shown to be effective in clinical practice (bleeding and surgery). New vWF products almost devoid of FVIII are now under evaluation in clinical practice. Although thrombotic events are rare in vWD patients receiving repeated infusions of concentrates, there is some concern that sustained high FVIII levels may increase the risk of postoperative venous thromboembolism. Dosage and timing of vWF/FVIII administrations should be planned to keep FVIII levels between 50 and 150 U/dl. Appropriate dosage and timing in repeated infusions are also very important in patients exposed to secondary long term prophylaxis for recurrent bleedings.

A Social Worker's Perspective

Leonie Mudge, Haemophilia Foundation Victoria Social Worker

It was a privilege to be funded by HFA to represent the Australian Haemophilia Counsellors' and Social Workers' Group at the recent WFH Congress. Maureen Spilsbury, Senior Social Worker at Queensland Haemophilia Centre also attended from the group. Maureen chairs the WFH International Psychosocial Group. Outreach Workers Drew MacKenzie and Colleen McKay, New Zealand members of our group, also attended the Congress and the special interest group meetings.

I met many inspiring people, renewed friendships with others, shared many pleasant social events with people from around the world and enjoyed a ferry ride to Victoria, the capital of British Columbia, after the Congress. A major benefit of the Congress is the chance to socialise with so many representatives of various stakeholder groups.

A World Congress is like a marathon which needs much prior training. Many sessions commence at 7.00am and presentations continue until 6.00pm with sessions during the lunch break and barely time to touch base with colleagues who are giving presentations or exhibiting amongst the 1000 posters over the week of the Congress.

A selection of pre-Congress and Congress highlights are described below.

Parents Empowering Parents (PEP)

PEP is a Train the Trainer program which has been running in USA for 10 years. It is a parenting program designed to affirm existing parent/child behaviours while focusing on the unique problems faced by parents of children with bleeding disorders aged two years or older. It is delivered by haemophilia centre-based teams of a social worker and a nurse, joined by a parent peer facilitator. It can be run over ten weekly sessions, or completed over a weekend. Topics such as child management skill development, managing discipline in children with bleeding disorders thought to be more 'fragile' than their siblings, exploring parents' feelings about dealing with bleeding disorders, reducing the impact of bleeding disorders on the whole family and improving family communication are covered. The underlying principle of the program is to support families early, and enhance their capacity to meet the challenges as their child with a bleeding disorder grows.

Pre-Congress Psychosocial Session

Susan Du Treil, a social worker from New Orleans, led a session about how they had coped in the aftermath of Hurricane Katrina. In our small group discussion we also discussed the impact of the December 2004 Tsunami. Susan Du Treil emphasised the difficulty of not having a national database, when treatment centre computers went down. Usha Parathasarathy, India, reported the importance of the national database to contact relocated patients. The irony was that in India the disaster response resulted in greater access to treatment product than usual.

Whilst we would never want such a wide scale disaster, it was a very thoughtful discussion. As a consequence of their experience, the Louisiana Comprehensive Care Center refined emergency contact procedures.

Congress Session Highlights

Musculoskeletal & Quality of Life Measures

I have been closely involved with the Strength & Balance Research project funded by the Haemophilia Foundation Research Fund in 2005, both in recruitment, and in observing quality of life improvements from the prescribed exercise routine undertaken by participants. Our research team had included the Haem-a-QOL measure for adults in English developed by Sylvia Mackensen from Europe who is a member of WFH Psychosocial Committee and will advise Sylvia about the results of our use of her QOL measure. Presentations in the musculoskeletal stream supported the benefits of physiotherapy and exercise to help build better joints, stronger bones and muscles and lead to prevention of bleeds, better recovery from bleeds, and slower development of arthritis, and to help patients cope with painful joints.

Kristy Wittmeier, from Canada, gave an excellent presentation about the threat of inactivity to musculoskeletal development. Being overweight as a child will impact on joint development and contribute to later problems. Apparently 40% of bone mass forms during adolescence. Several speakers emphasised the importance of exercise when recovering from a bleed. This could be back-up exercise using other parts of the body. Kathy Mulder, from Children's Hospital, Winnipeg, Canada, emphasised the importance of stopping the bleed as soon as possible and keeping blood away from cartilage and preventing future bleeds.

Ageing and Haemophilia

The ageing population clearly presents new challenges for the haemophilia community, and for haemophilia centres in particular as they need to be capable of recognising and managing the diseases associated with older people.

Co-morbidity

Sessions on ageing and the co-morbidity of health problems for older men with haemophilia were of great interest. In a session co-ordinated by A/Prof Alison Street, the emphasis was on the need to create a treatment model to co-ordinate the many specialties involved to treat a range of health issues, including cardiovascular disorders, prostatic and renal disorders, diabetes and cancer and arthropathy requiring orthopaedic surgery.

Falls and Balance Risk

Dr Keith Hill, from the National Ageing Research Institute in Melbourne, presented preliminary results from his research indicating that people with haemophilia are at greater risk of balance dysfunction and falls. He identified that need for exercise programs, medication review, home environment safety modifications, vitamin D supplementation and vision correction as effective responses to help people build stability and physical strength and maintain independence.

Heart Disease

Cardiologist, Dr Bruce Sussex, stressed the need for better data on haemophilia and heart disease. In a rural community in Newfoundland, he found people with haemophilia had higher average body mass index and higher incidence of diabetes, hypertension, and heart disease compared to a control group. Mary-Frances Scully also presented from a cohort of patients in Newfoundland, and was interested to hear about the development of the HFA Tai Chi and Yoga DVD to inspire gentle exercise for adults with bleeding disorders.

Socioeconomic, Quality of Life and Other Factors

Another session on ageing was approached from the perspective of the patient's quality of life. Mike Carnahan, from New Zealand, stated that 64% of people with haemophilia are without work after 45 years of age, compared to 25% in the general population. There are likely to be a range of socioeconomic needs – help with aids to daily living, transport, support for voluntary activities and particularly activities to help manage arthritis, such as hydrotherapy and light exercise programs. People may have partners or carers, but their carers may die or become less able to assist as they become older and develop their own needs for more care.

Ageing and the Cost of Health Care

Dr Eric Berntorp from Sweden reinforced the message that good early care pays dividends as life expectancy increases, not only in quality of life, but also in terms of the cost of health services, with less need for surgery, pain relief and institutional care. He noted that if men with haemophilia are blood borne virus-free, not overweight or smokers, they will be most likely to die of cancer, as haemophilia is a natural protector against heart disease.

Pain Management

Up to 40% of haemophilia patients experience chronic pain. The complexity of this warrants multidisciplinary intervention by pain specialists, psychologists, and occupational therapists. The importance of exercise in its role to release endorphins and the message to keep moving, even on bad days was considered critical. David Stephenson, an Australian physiotherapist working in Kent, emphasised the importance of having the correct orthotics, and aids to daily living. David was a contributor to the information booklet and DVD: Living with Haemophilia Joint Pain which has recently been produced by The UK Haemophilia Society.

Recruiting Young People Into National Member Organisations

It was wonderful to hear Paul Bonner talk about the Australian experience of mentoring youth and promoting our Australian youth group. Also in that session youth were invited to join others in cyberspace. Check www.Los-Bleedos.net for information and opinions on job interviews, education, dating etc.

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It was great to talk with some of the enthusiastic, Australian youth representatives at the Congress dinner.

Awards

Dr Bruce Evatt was amongst those honoured at an Awards Ceremony for his scientific achievements and outstanding contribution to the global haemophilia community. Dr Evatt ended his 10 year term as Vice-President of Programs on the WFH Executive Committee. Amongst his principal achievements was the groundbreaking 1982 discovery of the dangers of blood borne viruses like HIV/AIDS in the haemophilia community and other blood transfusion recipients, and research demonstrating that heat treatment of factor concentrates inactivates HIV.

Congress Thoughts From A Physiotherapist

Brendan Egan, Haemophilia Physiotherapist, Royal Children's Hospital Melbourne

My first impression of this conference was that it was huge. It is amazing, and yet comforting, to know that so many people from different nationalities and backgrounds would come together for the sole purpose of trying to improve haemophilia care. This was my first trip to the world congress and I was impressed.

When I reflect on the many aspects of care particularly related to the musculoskeletal system that were discussed at the conference, there are some that seem of particular relevance to Australia.

The physiotherapy pre-conference day was a great opportunity for me to finally meet many physiotherapists who I had heard so much about. The discussion that day was very beneficial to my care of the haemophilia patient. We listened to speakers who were discussing their management of patients with little or no use of factor replacement. They had good results in improving the range of motion of large joint contractures and in reducing recurrent bleeding episodes. They improved the contractures with serial casting over a long period of time. They would do this slowly and this would minimise the chance of causing a rebleed.

More importantly they placed a huge emphasis on exercise (which is something the Australian and New Zealand Physiotherapy Haemophilia Group, ANZPHG, is very supportive of). A graded exercise program was used to rehabilitate a joint or limb following a bleed or bleeds. Exercise was also then strongly encouraged in these patients on an ongoing basis to reduce the possibility of rebleeding. Of course exercise formed the basis of their physiotherapy education, trying to instill good exercise habits from an early age.

Across the whole conference there were many people who spoke about the importance of exercise and of playing sport - however what sport to play is viewed differently. Some people were very prescriptive, saying a person with haemophilia should not play some sports but can play others. One speaker flatly said no to fencing, however I can report that there is a young man with severe haemophilia in Victoria who has been fencing safely at a very high standard for the last few years. There are others who feel like the ANZPHG - that the choice of sport is individual; basketball may be appropriate for one but not another, and that encouraging sport participation is an important aspect of haemophilia care. The experience of our colleagues in the developing world demonstrates that a fit and strong body is an effective way of reducing bleeding episodes. In Australia factor replacement gives people with haemophilia even more options for sports participation.

With regard to the orthopaedic management of a bleed there were two issues which I think require further discussion and investigation. The first is the use of synovectomy to manage the target joint and arthropathy. The second is the use of aspiration (or removal of blood from the joint) in the very acute stage of a bleed to assist in the reduction of cartilage damage caused by exposure of the cartilage to blood and inflammatory mediators.

I came away from the conference keen to improve the education of my patients and their families to the most appropriate management of bleeds. The message from other physios in developed countries was that some families are relying on factor to manage a bleed, and yet forgetting that there is so much more that can be done. Rest, ice compression and elevation (RICE) are still a fantastic way to assist in the management of a bleed. Correct rehabilitation following the episode will aim to ensure that this bleed does not happen again. Factor replacement is only one aspect of the overall management.

My Congress Experience

Natashia Coco, Development Manager, Haemophilia Foundation Australia

Fundraising Strategies In A Competitive Environment

Aliakbar Tchupan from the Iranian Hemophilia Society spoke about the basic principles in fundraising and the philanthropy landscape. He stressed that a rapidly expanding non-profit sector and changing donor behaviours are creating a new and more competitive environment for securing charitable support. Beyond establishing or maintaining good relationships with donors, we need to do continue translating passive support into passionate giving and advocacy!

Rosalind Franklin, Development Manager, WFH, stressed the importance of joining forces and collaborating with other NMOs to fundraise, being an excellent way to leverage limited resources, advance organisational goals, expand fundraising horizons and raise more money. Collaborative fundraising has a better chance of succeeding when organisations share interests and values, and have a high level of trust.

Factors influencing the success of collaborations:

- Mutual respect, understanding and trust
- Partners see collaboration as in their own self-interest
- Sufficient resources – staff, materials, time and financial investment
- Appropriate cross-section of partners/multiple layers of participation
- Clear roles and policy guidelines
- Open and frequent communication
- Shared vision/concrete, attainable goals

Challenges:

- Power struggles
- Low trust
- Apathy and non-participation
- Personnel changes
- Inadequate decision-making
- Inadequate communication
- Not reaching stated goals
- Expect misunderstandings

Evaluating success:

- Revenue raised
- Skills gained
- Partner satisfaction with collaboration
- Awareness increased
- New fundraising avenues opened

Trish Domenic from Hemophilia Of Georgia, Inc (HOG), Atlanta, showcased successful events, both past and present. The society has in the past conducted a Fashion Parade and Poinsettia Sales. These events were very successful while they were running, but it came a time when the events were too costly, with too much staff and volunteer time, making the events no longer viable.

HOG currently runs a successful golf tournament raising over US$425,000. The tournament began in 1982 and to date over 400 golfers participate in the day event, with corporate sponsorship approximately US$511,000. Other fundraising activities held in conjunction with the event are auctions and raffles, including a prize of an airline ticket.

Rob Christie, HFA Executive Board member and WFH Vice-President of Finance, spoke about Fundraising: Donation drive strategy in a competitive environment. He displayed fundraising in Australia and in particular HFA. HFA has a successful fundraising program including direct mail campaigns, trusts and foundations, special events and building donor relationships and corporate relationships.

Transitioning Adolescents Living With A Bleeding Disorder Into Adulthood: More Than a Referral

Presenter - Miriam Kaufman, Hospital for Sick Children and the University of Toronto, Ontario, Canada

Transition is a process not an event. It is necessary to also see the parents' needs as well as the adolescents. The essence of adolescents is change.

Adolescents go through normal life changes including: educational, vocational, philosophical, sexual, family, recreational and relationships.

Developmental issues include: cognitive development, philosophical and moral developments, physical developments, identity developments and executive function

The Hospital for Sick Children and the University of Toronto worked together in developing a sustainable model for transition. Key aspects of the model are -

- Education – about condition and treatment
  - Adolescents need to know about their exact condition e.g. Haemophilia B severe, and about their treatment e.g. products, dosage, frequency etc…
  - This is the beginning of the adolescent taking control of their disorder
- Familiarity with adult providers and the health system
  - Meeting health professionals and how the system works in that particular hospital/centre
- Transfer procedures
- Skill development
- Referrals for vocational counselling
- There are a variety of avenues the transition and information:
  - One to one clinics
  - Transition Days
  - Psycho-educational groups for skill building, mentoring and meeting others

Presenter - Danna Merritt, Hemostasis Thrombosis Center, Children's Hospital of Michigan, MI, USA

A transition protocol was developed between 1990 and 1997 with the assistance of parents and patients living with bleeding disorders through the use of ad-hoc advisory committee meetings. The protocol was implemented in 1999 and has been used consistently in the treatment centre since that time.

Protocol Features:

- Process occurs over a 8 year period
- Has an empowerment focus for the person with haemophilia
- Has parental participation
  - Provides support; emotional, educational and informative
  - Over time the person with haemophilia is seen by staff at the adult hospital by himself (without parents), this is the key to independence
- Learning to self treat before the transition is the key – we stress this importance
- Knowledge and counselling is given in regards to; sexuality and sexually transmitted diseases, sports and career counselling

Forty previous patients of the Hemostasis Thrombosis Center who have been transitioned into adult treatment since 1999 were surveyed in January 2006 regarding their opinions, thoughts, and advice regarding their transitioning experience.

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This is to evaluate the program and the process. Results at present are not available as yet.

WFH centre twinning

The WFH Centre Twinning Program helps emerging haemophilia treatment centres develop partnerships with well-established centres. Twinning can improve diagnosis and clinical care of patients with bleeding disorders through coaching, training, and transfer of expertise ultimately leading to improved quality of life for patients. Twinning enhances the profile and recognition of treatment centres in emerging countries, which may be valuable in increasing awareness of government and local media. The Centre Twinning Program can also benefit centres in established countries by giving their staff the opportunity to regain familiarity with clinical problems rarely encountered in their own countries as well as experience of new cultures. Currently close to 60 treatment centres around the world are linked through the WFH Centre Twinning Program involving hundreds of dedicated volunteers from the global haemophilia community.

There are three important components of a successful twinning relationship:

1. Close collaboration with the national patient organisation

2. Promotion of the comprehensive care model.

3. Involvement of a wider regional haemophilia community in twinning.

The Children's Hospitals and Clinics of Minnesota, Minneapolis, USA and Armenian Association of Hemophiliacs

In 2003, a Memorandum of Understanding (MoU) was signed between the WFH and the Ministry of Health of Armenia (MOH). According to this MoU, the MOH agreed to start a National Haemophilia Care Program in 2004 and to supply factor concentrates for the first time. The cornerstone of the national program was to establish a first Haemophilia Treatment Centre (HTC) at the Haematology Centre in Yerevan, the capital. Specialists are being trained abroad and reagents supplied for diagnosis. To support all the activities, centre twin representatives from The Children's Hospitals and Clinics of Minnesota, Minneapolis, USA, are essential to guide and coach the new haemophilia specialists. Moreover, most of the components of the National Haemophilia Care Program would not have been possible without the cooperation of the Armenian Association of Hemophiliacs (AAH) and the medical staff. In coordination with both, physiotherapy and nursing workshops have been organised. Outreach to persons with haemophilia and local treaters of two regional towns has also been conducted, while educational material such as Hemophilia in Pictures have been translated into Armenian and published as part of this team work. The patient organisation did some fundraising to pay for the new equipment at the HTC and a national patient registry was created with the collaboration of both groups by building upon the data the AAH already had. Finally, government and media relations are also jointly organized by both the AAH leaders and the HTC director who have good contacts with them.

Annie Borel-Derlon from France spoke about the involvement of a wider regional haemophilia community in twining. France twinned with Morocco, two haemophilia treatment centres, Casablanca and Rabat. The main aim of the twin was to improve access to treatment and medical are and re-organisation of the National Member Organisation.

The expected outcomes of the twin were the evaluation of product needs, training haemophilia health professionals, and to help with medical assistance.

There was a need for regional twinning, and together a Mediterranean network for haemophilia was developed - countries included; Algeria, Lebanon, Syria, Egypt and Tunisia. A symposium with representatives from each country was hosted. This was a challenge and many things were learnt from each other. Common problems on a wider network were identified.

Susan Zappa advised that, Cook Children's Medical Center, Fort Worth, Texas, USA is twinning with Lima, Peru. Susan stressed that twinning is a team effort and must include the following: the patient and family, haematologist, nurses, social worker and physiotherapists. They faced many challenges, including medical staff understanding, assembling a dedicated team in Lima, dealing with insurance and government and most especially culturally aspects.

The twin has brought patients and families to the clinic – they are now able to be accessed and each patient is evaluated.

The key to twinning is team work, respecting and understanding cultural differences and getting national government to agree to haemophilia care and treatment.

Recruiting Young People into National Member Organisations

Paul Bonner, Chair of the HFA Youth Committee was invited to speak at this session about the Youth Leadership and Mentoring Program in Australia.

Speakers also included Siddhartha Ojha from India who spoke about the experience of the Calcutta youth group, and Christian Krogh from the Danish Hemophilia Society launched and invited youth internationally to be part of the LosBleedos cyberspace.

Refer to *Youth News* for more information on these programs and the sessions.

Australian Haemophilia Nurses' Group

The following article was provided by members of the Australian Haemophilia Nurses' Group, which is auspiced by HFA. HFA receives funding from the Australian Department of Health and Ageing for support to specialist health professionals' groups. If you would like further information on the group, please contact either of the co-chairs whose contact details you can find at the end of the article.

The Australian Haemophilia Nurses' Group was first convened in 1988 and was formerly known as the Haemophilia Foundation Australia Nurses' Association. Since its establishment the group has provided a forum for nurses throughout Australia working with the haemophilia community to meet and share experiences.

The goal of the group is to continuously improve haemophilia nursing care and services within Australia. In order to work towards this goal the following objectives of the group were developed:

- To foster collegiate relationships amongst haemophilia nurses on a state, national and global level;
- To provide a reference point for professional groups;
- To support ongoing education for all haemophilia nurses;
- To act as an advisory panel for haemophilia support groups;
- To conduct and promote clinical research;
- To coordinate and advocate for multi-disciplinary care;
- To raise awareness of haemophilia within the health profession and community;
- To work in partnership with national and state bodies representing haemophilia;
- To foster mentorship for beginner nurses.

Membership of the group is open to any Registered Nurses who provide a clinical practice role within the haemophilia field. The group meets annually and communicates throughout the year via email and telephonephone conferences.

The group last met at the 13th National Haemophilia Conference held in Melbourne in September 2005. Thirteen Registered Nurses attended this meeting from adult and paediatric haemophilia centres with all states and territories represented. Four nurses also attended the meeting from New Zealand, which allowed for exchange of experience and knowledge.

The World Federation of Hemophilia Nurses' Committee representative, Fiona Rennison (Royal Prince Alfred, Sydney), provided a valuable insight to the group on the role and function of the WFH Nurses' Committee. Educational reports and feedback was also provided by Megan Walsh (The Alfred, Melbourne) and Beryl Zeissink (Royal Brisbane) on their experience and areas of interest from their attendance at the Baxter Global Nurse Symposium held in September 2005 in Dublin, Ireland. The reports provided an opportunity to share the knowledge gained about current care provided by haemophilia nurses around the world, as well as an opportunity to share resources used in International Haemophilia Treatment Centres. Salena Odlum (Royal Children's Hospital, Brisbane) and Mary Brasser (NZ) also presented informative reports at the meeting.

An important aspect of the meeting is also the discussions around areas of improvement and how different centres have tackled these aspects of care. Highlighted from these discussions is the need for a universal approach and coordinated resources to ensure all those affected by a bleeding disorder have access, regardless of which state or territory they reside. One area that is currently being developed is a national emergency treatment card. A working party has been established with representatives from Qld, NSW, Vic and SA with both paediatric and adult centres represented. The aim is to work with both Australian Haemophiila Centre Directors' Organisation and the Data managers' group to produce a card that will help to improve the information to and care provided by Emergency Departments. This will enable those with a bleeding disorder to receive appropriate and timely treatment. The group is working towards this and hopes to provide more information on its availability and use in the next six months.

The next meeting of the Australian Haemophilia Nurses' Group is planned to be held in Melbourne, 7-8 September 2006.

If you are involved in a clinical haemophilia-nursing role and are interested in attending or would like more information, please contact either of the co-chairs:

Anne Jackson:
cywhs.haemophilianurse@cywhs.sa.gov.au

Megan Walsh:
Megan.Walsh@alfred.org.au

Australian Health Ministers' Advisory Council (AHMAC) Factor VIII And Factor IX Guidelines

Evidence-based clinical practice guidelines detailing treatment regimens and alternatives for people with haemophilia A, haemophilia B and von Willebrand disease have recently been published. The guidelines are intended to inform clinicians and people with haemophilia of the safest and most effective strategies using the best available evidence about:

- treatment products for prophylaxis
- acute bleeding
- surgical and dental procedures
- ante natal care and delivery of infants
- use of adjunctive agents
- managing inhibitors
- approaches to tolerisation

A copy of the guidelines can be downloaded from the National Blood Authority web site at http://www.nba.gov.au/articles/article_20060620_01.htm or contact HFA for a hard copy.

Bone Health In

Catherine van Neste

Catherine van Neste is a physiotherapist at Hopital Enfant-Jesus in Quebec City, Canada. The following article was published in Hemophilia Today, Vol 40 No 3, the journal of the Canadian Hemophilia Society.

Osteoporosis a disease of the elderly, isn't it? Yes, quite right! Osteoporosis is a loss of bone density, and the symptoms appear mainly in older persons. But in order to lose bone, you first have to have build up bones over the course of your life! And that's what we're concerned with here.

We are born with a certain bone density, and our bodies add more as we grow. The most critical period for bone growth is the pre-puberty years, ie between 11.5 and 13.5 in girls, and between 13.05 and 15.05 in boys. Children build as much bone (26%) during this time as they will lose during their adult lives.

How do you build bone? Well, the easiest way is to let nature do its work. Growth hormones will do the job. But if you grow too fast you end up with fragile bones that could give you problems in your retirement years. Another way is to take calcium supplements; however, studies have shown that the positive effects of these supplements do not seem to last beyond the treatment period. The last solution – the best, though perhaps not the easiest – is weight bearing physical activity.

Weight bearing physical activity is any activity that is done on the feet and produces an impact with the ground corresponding to at least 3 times the body weight. For example, walking produces an impact of 1.1 times body weight, running 2.5 to 3 times, jumping 6 times, and gymnastics 12 to 14 times body weight. Weightroom training, swimming and cycling are not regarded as weight bearing activities.

Studies show that this kind of activity during the pre-puberty period promotes more bone production and thus increases bone density. The effect is clearly less pronounced if the activity is done later in life, that is, in adolescence or during adulthood. The most active children have more bone density than children at the same level of maturity who are less active.

But will doing these activities during childhood protect your bones? Everything depends on the level of activity you maintain during your adult life. One thing is certain, however: the higher your bone density, the stronger your bones will be, even after normal loss associated with age.

What about bone density in haemophiliacs? The fact is that children with severe haemophilia may show a moderate reduction of bone density compared to other children, and this reduction is more pronounced in

children who present joint changes. The most likely cause appears to be a lack of weight bearing physical activity. In fact, children with haemophilia have had a very limited choice of sports activities for decades, and haemophilia associated arthropathy reduces their options even further. Hepatitis C can be a risk factor for osteoporosis, but opinions on this are divided.

In light of the above, osteoporosis could be called a childhood disease that manifests itself in the elderly. It is important to remember that the pre-puberty period is a unique opportunity to arm yourself against this disease by doing more weight bearing activities. But what can you do when you have to cope with haemophilia? The purpose of this article is certainly not to set off alarms; the idea is to get people thinking about it. Weight bearing activities are problematic when you have to deal with a painful target joint. The main recommendation is that each person should take part in an activity carefully selected for his or her restrictions, under supervision and with optimal prophylaxis. With regard to post-bleeding immobilisation, which is generally fairly short, it is absolutely necessary and probably not a major factor in the onset or prevention of osteoporosis. No study has demonstrated that non weight bearing activities, such as swimming, slow down bone growth. You can continue to engage in this kind of activity, but watch for opportunities for weight bearing activities when joint condition returns to normal. Adequate nutrition may be a valuable ally in our quest for optimal bone density. The biggest challenge in the coming years will be to better classify sports activities in order to make them accessible and safe.

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The biggest challenge in the coming years will be to better classify sports activities in order to make them accessible and safe

the body weight

Haemophilia Foundation Research Fund

A number of research applications were considered for funding by the HFA Research Committee Chaired by Dr Scott Dunkley, Director of the Haemophilia Centre at Royal Prince Alfred Hospital in Sydney. HFA has provided two research grants for valuable research in 2006-2007 which is expected to have significant benefit to the bleeding disorders' community to:

Dr Michaela Lucas (Royal Perth Hospital, WA) - $50,000 for: *Characterisation of cross-genotype HCV-specific T lymphocyte responses in HCV-exposed haemophilia patients –implications for the design of a protective vaccine and immunotherapy*

Prof Paul Komesaroff (Monash University, Victoria) - $25,000 for: *The social and ethical dimensions of genetic testing: a longitudinal study of the haemophilia community.*

More information about these projects will be published in the next edition of *National Haemophilia*

Youth Leadership And Mentoring Program Training Weekend

The Youth Committee is organising and planning a training weekend. Young people across Australia are invited to attend the weekend. The weekend is aimed at males and females over the age of 14 years. If you are interested in attending the weekend and seek funding, speak to your local foundation for support.

For more information on the weekend and the program see the enclosed *Youth News*.

To see more about what the HFA Youth Committee is doing to support young people with a bleeding disorder, see the *Youth News* supplement in this newsletter.

Resources

Hepatitis C Is Everybody's Business

This free resource, available in the following languages, has been produced by the National Hepatitis C Project for people from culturally and linguistically diverse (CALD) backgrounds:

Arabic, Bosnian, Chinese, Croatian, English, Greek, Indonesian, Italian, Khmer (Cambodian), Korean, Macedonian, Portuguese, Spanish, Thai and Vietnamese

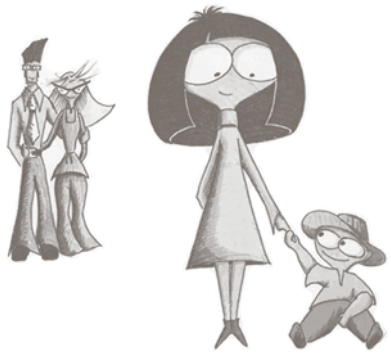
Developed by the Multicultural HIV/AIDS and Hepatitis C Service, this brochure aims to raise awareness of hepatitis C and is targeted to the general community, injecting drug users and young people from CALD backgrounds in Australia. Transmission, testing, treatment, prevention and support are some of the topics covered in the brochure.

Please contact HFA on freecall 1800 807 173 or email hfaust@haemophilia.org.au if you would like a copy forwarded to you.

Sassy….. becomes a big sister

This book, written by Kate Evans and illustrated by Andy Barr, tells the story of Sassy who has a new baby brother with haemophilia. Sassy describes her roller coaster ride of emotions, including jealousy, and how she copes as a sibling. It is suitable for children aged ten and under.

The book is available through Kate's website www.design-graphix.net/Fuego/sassy.htm at a cost of £4.99 including postage.



Camps

Victoria

19 families from all over Victoria (including a family from Hong Kong) attended the Camp at The Portsea during April 2006.

The Portsea Camp, is right on the beach and proved to be a fantastic place where families could 'spread out' and enjoy the facilities, ovals, courts, beach, etc. Over the weekend, families had fish and chips on the beach, activities such as the giant swing, high ropes and the Flying Fox, and the kids had an '80s disco and Star Wars night games. Mothers and fathers also had an opportunity for Secret Women's Business and Secret Men's Business enabling them to get together with other parents. Haemophilia nurses ran 'The Jewel in the Crown' – self infusion workshops for children to learn to self-treat.

The camp received positive feedback from children and adults at the camp. Often the children can't wait till the next camp! The weekend certainly achieved its aim in helping support people with bleeding disorders, their families and carers.

Western Australia

30 parents and children attend the Family Camp at Ern Halliday Recreation Park in Hillarys in April 2006.

The camp was the first of its type for many years in WA. It gave families the opportunity for social interaction, peer support and education.

Over the weekend many activities were organised such as: team building tasks, a BBQ camp fire dinner, indoor rock climbing, face painting, a Flying Fox, and art and crafts.

The weekend was most successful and everyone, especially the children, is looking forward to next year's camp!

Thank you to the trusts, foundations and donors who kindly supported these camps.

Calendar

Hepatitis C Awareness Week
Australia 1-6 October 2006
ph 03 9385 9107
email heather@hepcvic.org.au

Haemophilia Awareness Week
Australia 8-14 October 2006
ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au

Australasian Sexual Health Conference
Melbourne 9-11 October 2006
ph 02 8204 0770
fax 02 9212 4670
email conferenceinfo@ashm.org.au
www.sexualhealth2006.com.au

18th Annual ASHM Conference
Melbourne 11-14 October 2006
ph 02 8204 0770
fax 02 9212 4670
email conferenceinfo@ashm.org.au
www.ashm.org.au/conference

Youth Leadership and Mentoring Program
Launceston, 12-15 October 2006
ph 03 9885 7800
fax 03 98851800
email hfaust@haemophilia.org.au

14th National Symposium on Hepatitis B and C
Melbourne 18 November 2006
email eleanor.belot@svhm.org.au

14th National Haemophilia Conference
Canberra 4-7 October 2007
ph 03 9885 7800
fax 03 98851800
email hfaust@haemophilia.org.au

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

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

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