National Haemophilia

Haemophilia Foundation Australia www.haemophilia.org.au

No. 160, December 2007

14th Australian & New Zealand Haemophilia Conference

Canberra 4-7 October 2007

bleeding disorders ~ achieving success to last a lifetime

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HAEMOPHILIA FOUNDATION AUSTRALIA

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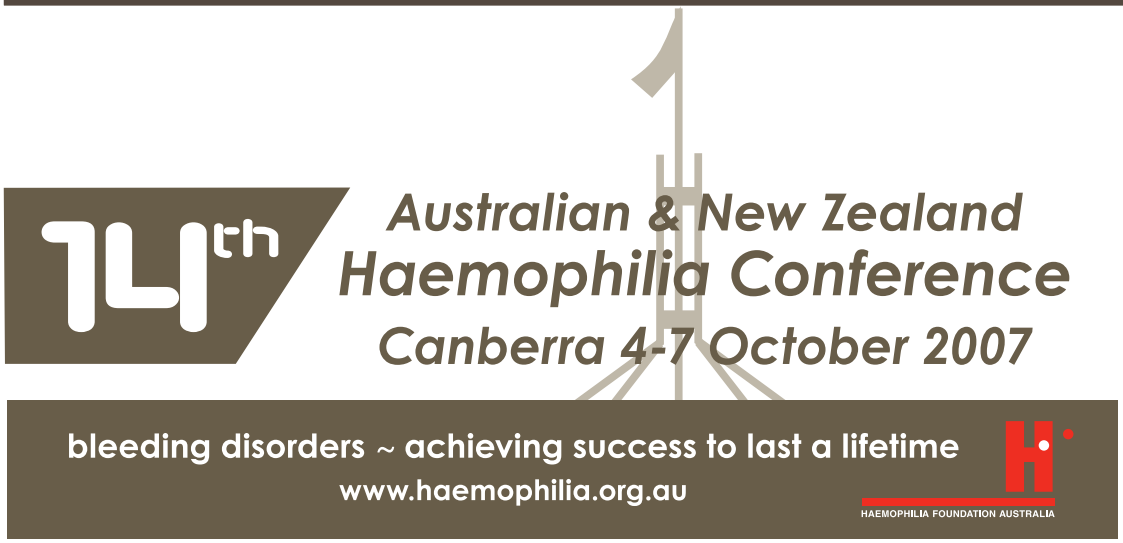

The 14th Australian & New Zealand Haemophilia Conference held at Hyatt Canberra from Thursday 4 October – Sunday 7 October 2007 has been described as a great success by those in attendance!

The Conference brought Australians and New Zealanders with an interest in bleeding disorders together to learn more about the treatment and care and future directions.

The multidisciplinary program featured presentations by Australian, New Zealand and international experts. HFA is grateful for the support of the Conference Program Committee, chaired by Dr Scott Dunkley from the Royal Prince Alfred Hospital, Sydney.

Presentations and the abstract book are available for download at www.haemophilia.org.au - for a hard copy of the abstract book please call HFA on 03 9885 7800 or email hfaust@haemophilia.org.au.

The *Welcome Cocktail Party* held on Thursday evening started the Conference with an informal gathering for people to meet and greet. HFA President, Gavin Finkelstein took the opportunity to thank the Foundation's Corporate Partners for their ongoing support to the organisation and to thank the official sponsors of the Conference and open the exhibition.

The *Remembrance Service* has been a long tradition at national haemophilia conferences and is a special time set aside for people from all parts of the bleeding disorders community to remember friends and relatives, and the people they have cared for, who have died and for those who are living with complications of bleeding disorders and blood borne viruses.

The non-denominational service was planned by Fred Wensing and Clare Reeves from HFACT and facilitated by Jane Foulcher, an Anglican Minister. The service was held at Nara Park which is a beautiful Japanese tea garden alongside Lake Burley Griffin. In the twilight of a lovely spring Canberra evening Maria Wensing, Craig Bardsley, Grant Hook and Gavin Finkelstein presented short readings to reflect the thoughts of their friends and loved ones. At the conclusion of the service, everyone present lit a candle in their memory.

The Gala Dinner was a special evening to remember for 200 of the Conference delegates who attended. The dinner was held at the Hyatt and featured Harri Bandu and his quartet who entertained guests during the evening.

Please see reports on the Conference elsewhere in this edition of *National Haemophilia*.

Gavin Finkelstein is President of Haemophilia Foundation Australia, and President of Haemophilia Foundation Western Australia.

PRODUCT CHOICE IN AUSTRALIA

Gavin Finkelstein

The decision in 2004 to make recombinant treatment products available to all people with haemophilia in Australia regardless of age and blood borne virus status was critical. We needed a supply of the safest treatment products for people with bleeding disorders. Since 2004 most people with haemophilia have been able to choose the most appropriate treatment product for their situation. Most people with haemophilia now use recombinant clotting factor, although some continue to use plasma derivatives for clinical reasons or simply because they wish to do so. People with von Willebrand disorder are still reliant on plasma derivatives, but steps to make these safer from risks of viruses and prion transmission have strengthened. These products too, are now considered very safe.

HFA acknowledges the commitment of Federal and State governments to enable patients to use best practice treatments in this country. The National Blood Authority has been instrumental in ensuring a constant and reliable supply of appropriate treatment products to meet the needs of our community through the processes developed under the National Blood Agreement. HFA supports the redevelopment of the Australian Bleeding Disorder Registry and will play its part in ensuring responsible and accountable use of our treatment products.

HFA's position is that treatment products which are registered for use in Australia should be available to our community

People will make their choices in consultation with their treating doctor. This is how it should be. There are several different options for some people and treatment product decisions are made on the basis of different factors. Although some people still have little choice due to their particular condition or circumstances, many of us do have a wider range of products to choose from than ever before – I hope everyone has taken the opportunity to discuss the merits and advantages of each relevant treatment product available with their doctor. Decisions about the starting material, how the product is manufactured, safety and efficacy are important for us all, and some people are also keen to think about the implications of vial size, the reconstitution process, size of packaging or the ease of storage. These are all questions which should be discussed with your doctor.

New products or improvements to existing products will continue to emerge. In the last year several additional plasma derived products have been registered by the Therapeutic Goods Administration for use in Australia, including one specifically developed overseas for the treatment of von Willebrand disorder. HFA's position is that treatment products which are registered for use in Australia should be available to our community and in consultation with their treating doctor patients should make an informed decision about the best treatment for them. HFA will continue to advocate to governments to ensure a range of the best treatment options are available.

Gavin Finkelstein is HFA President.

2007 HAEMOPHILIA CONFERENCE

Gavin Finkelstein

The 14th Australian & New Zealand Haemophilia Conference was my first conference as HFA President, so I saw it in a different light to what I had in the past. The conference presents a unique opportunity for the community, clinicians, other health providers, government, pharmaceutical companies and anyone else associated with haemophilia to get together in one place. It was great catching up with friends from all over Australia and New Zealand who I hadn't seen for a few years and to find out where they are at and what was happening in their lives.

Prior to the opening of the conference, AHCDO, the nurses, social workers and physiotherapists each had their annual meeting which is a valuable way for them to exchange views on treatment and care amongst their peers. Before these meetings, many nurses and social workers from and a few parents around the country participated in the Parents Empowering Parents Program conducted for the first time in Australia by facilitators who came from the US. We were delighted to offer this opportunity and look forward to the follow up training around the country in 2008.

I was pleased to welcome everyone to the conference at the Welcome Cocktail Party and to recognize the valuable participation of the conference sponsors and exhibitors. The Exhibition was open for all to browse, ask questions and avail themselves of the various education opportunities and was a central meeting point throughout the next two days of the conference.

The next morning the conference was officially opened by Deon York – President HFNZ and myself and was followed by a plenary chaired by Program Committee Chairman Dr Scott Dunkley, where associate Professor Ian Kerridge spoke on the thought provoking topic of "Ethnomics", *identify and agency in haemophilia* followed by Dr Kathelijn Fischer who presented on "The role of health related quality of life for outcome assessment in haemophilia". The rest of the day was filled with various interesting and educational sessions with something of relevance for all who attended.

Someone commented to me that it was helpful to have people living with bleeding disorders participating in several of the sessions as their experiences made the sessions even more meaningful. The conference program committee worked hard to ensure the sessions were relevant.

The first day ended with a light hearted session titled "You won't die laughing", which promoted the benefits of laughter, and reminded us all of the need to reflect with humour on the difficult things we are all dealing with.

The Remembrance Service in the beautiful Nara Park at sundown was an emotion charged time of remembrance for those in our community who have passed away before their due time.

That evening I was privileged to share in the presentation of the Ron Sawers Award to A/Professor John Lloyd for his long service to the haemophilia community at the Gala Dinner. His long CV and list of publications and the warm reflections about his service are evidence of a health professional who has dedicated his working life to improving the lives of his patients. We are most grateful to him and wish him well in his retirement.

Day Two of the conference began with a plenary chaired by Dr John Rowell, with the speakers addressing two of the most discussed topics in haemophilia care being – "Individualisation of prophylactic treatment of severe haemophilia; when to start and when to stop" presented by Dr Kathelijn Fischer and "Pre-implantation genetic diagnosis and assisted reproductive technology in haemophilia" presented by Dr Penelope Foster. They both provided plenty of information on both topics for discussion. As with the day before, the day was filled with many interesting and thought provoking topics. The final plenary was probably the most heated session of the conference - it was titled "And what about the future?" The discussion could have gone on for hours on the future direction of haemophilia care and what we can do to ensure it continues to improve over time with new treatment products and more sophisticated care and services.

The conference was closed by Rob Christie Vice President Finance, World Federation of Hemophilia, Deon York and myself.

I thoroughly enjoyed the conference. My congratulations to all involved in the conference, especially HFA staff and all the speakers. Thank you to all those who attended and made the conference a great success.

I look forward to seeing as many of you as possible in Brisbane in 2009.

Justine Mamootil is a member of the Haemophilia Foundation Western Australia Committee and was a recipient of one of the 2007 HFA Vision and Leadership Awards.

2007 HAEMOPHILIA CONFERENCE

Justine Mamootil

My family and I arrived in Canberra on Wednesday evening. We had decided to stay with family to allow our children some reconnection time with relatives as we rarely get over to the eastern side of the country. We arrived late in the evening and picked up our hire car to drive to my sister in-law's house. We had a map of Melbourne, but not one of Canberra which made things a little difficult in the dark. We guessed our way (we thought!) to Holder (a suburb of Canberra) only to find that we were very lost and closer to Cooma! A phone call got us back on track.

On Thursday morning we were feeling a little out of sorts with the time difference. I soon had hay fever from the wattle trees in Canberra and I eventually had nose bleeds during most of the weekend.

At the Welcome Cocktail Party we were greeted by all our fellow Perth travellers and introduced to other members of Haemophilia Foundations. It was a great opportunity for me to meet another female with the haemophilia gene and be able to compare stories and ask questions.

I acquired hepatitis C almost 25 years ago and I was keen to attend the session on Hepatitis C Treatment and Care. Neil Boal, from Haemophilia Foundation Victoria, gave a great talk about his experience of treatment for hepatitis C. Dr Stephen McNally, from La Trobe University in Victoria, highlighted some of the psychological and social factors impacting on the decision of whether to start treatment. For me this is a very important question as I am a working mother with two children.

I was keen to hear more about a family's experience of the von Willebrand Disorder. Lorraine Bishop spoke of her son's initial misdiagnosis. She talked about her son Zac always being covered in bruises, and her Plunkett nurse being suspicious he was being mistreated. This reminded me of my own mother's experience of having a daughter with haemophilia. I too was always covered in bruises. My child health nurse became suspicious of my parents. I could sympathise with Lorraine and truly felt for her.

Earlier this year I applied for a Vision and Leadership Award from HFA. I was hoping I would be funded to attend the Canberra conference so that I could learn more about some of the issues which impact on me personally. When I saw the program I was particularly keen to go to sessions about women's bleeding problems. I have mild haemophilia B and I have had some haemophilia issues in my life. These issues are all female related.

In the Women's Wisdom session Belinda Burnett spoke of her daughter's experience of severe haemophilia. I had even more questions in my discussions with Belinda after her presentation. For most women with severe to moderate levels of haemophilia it is disillusioning that the health system rarely recognises women with haemophilia. For most mothers of these daughters with haemophilia there is a sense of guilt and worry about whether their daughter will be able to have children, and if so whether the pregnancy and delivery will be difficult.

The management of delivery in carriers and the management of the newborn should be a carefully well thought out plan and is best managed by a team including haematologists, obstetricians and paediatricians. Having a clinical team with experience treating people with bleeding disorders is comforting. I have been through cycles of menorrhagia and child birth on two occasions and I can only talk of my experiences and share these with others. My child birth experiences have been very positive. But for many women with severe to moderate levels of haemophilia there are difficult challenges. The health system needs to recognise that it is not "only boys that are born with haemophilia".

Menorrhagia is often a point of discussion at our women's breakfast get-togethers in Western Australia. Dr Julia Phillips discussed what a heavy menstrual cycle is, explaining that anything more than eight days of flow is a heavy menstrual cycle. She highlighted the impact of this on many women. Dr Phillips mentioned that approximately many women with von Willebrand Disorder are affected by heavy menstrual bleeding. She highlighted some of the non-surgical and surgical options available to treat menorrhagia. I felt there remains a lack of management strategies for women with bleeding disorders and menorrhagia.

The conference gave me a chance to reflect back on my difficult times in managing my own haemophilia. Having better care and management for women with haemophilia and ideally recognising that women as carriers of the haemophilia gene do suffer would be a positive step forward. Women suffer in a different way and it is often in a silent way. The conference gave women who had been suffering in silence the opportunity to speak out. Having the support of peers at the conference was reassuring for each of us.

I encourage you to apply for the next Vision and Leadership Awards. Without this Award I would not have been able to travel to Canberra and would not have been able to attend the conference. The conference was a great way for me to educate myself about haemophilia. I am also now better prepared to provide support to women who carry the haemophilia gene and who are encountering difficult issues.

For more information on sessions held at the 14th Australian & New Zealand Haemophilia Conference please see: www.haemophilia.org.au/knowledge/cid/114/t/knowledge.

Neil Boal presented at the Conference on his very personal journey of hepatitis C treatment which was published in the November 2007 Newsletter of Haemophilia Foundation Victoria.

HEPATITIS C TREATMENT

Neil Boal

Thanks for the opportunity to speak today about my experience with hep C and undergoing treatment.

It seems that the word 'success' is not a term used often in haemo care. Terms like 'managing' and 'maintainence' are the key words associated with bleeding, pain and joint care. So it seemed to be the same when blood borne viruses came to light.

For me, some 30 years ago, my parents became aware that I had been exposed to a type of hepatitis but it wasn't A or B so the term Non A-Non B was born. However there was never any indication this would pose any threat to me and not much more was thought about it.

Racing into the 80's I was also hit by the HIV epidemic. Of course we all know the fear and hysteria that followed, and continues to this day to a lesser degree. The obvious potential impact on my health was all consuming even to the point where my haemophilia was just a relatively minor concern.

Into another decade (an achievement in itself) and 1990 brought the official diagnosis that Non A-Non B was in fact hep C. So as we worked into the alphabet, had giving it a name, (or a letter), changed the diagnosis? No, was the answer. Benign was the consensus. Besides anyone who had HIV as well was on borrowed time anyway.

Darting here to the present, we can all plainly see what the real impact of hep C has become. So much so, that from the young adults to us crusty oldies, hep C is dominating haemophilia care.

I really can't tell you when hep C started having an impact on my health. As I hit my 30's my joints were deteriorating and bleeds were increasing, and then at 33 I was hit with PCP or pneumonia. I thought my time was up but I responded well to treatment and recovered, (as you can see). But that was obviously HIV related. Since then, combination therapies and lifestyle changes have kept my HIV under control.

However as the drugs were introduced and my body was dealing with more joint pain, I became nauseated and terribly tired. I lacked energy, motivation and any real get up and go. It was becoming harder to work and even harder to do things that I loved. There were plenty of reasons to feel tired, both physical and emotional, but we could never pinpoint exactly why.

Even as the effects of long term hep C infection became apparent, I think it added just more pieces to the puzzle. What was becoming clear was that I was feeling unwell. But there was nothing we could do on the hep C side of things anyway. Like with HIV, blood tests carried our hopes, and our highs and lows would follow a similar pattern to the results. Good results lifted the mood whereas bad results would leave you flat. LFT's, ALT's, PCR's, viral loads and genotypes were becoming common speak for patients in the waiting rooms.

These patients would often become mates, such was the regularity of our check ups. However the down side to this was watching my peers slide downhill, and feeling that I would soon follow. That was another emotional trigger that has left its mark on me and many others. Not surprisingly, not one of us could work out exactly what was causing all of the symptoms, but hep C was now sharing the blame.

When Interferon came along, some hopes were raised in treating the hep C. Some brave souls embarked on this gruelling journey that in the end showed little promise at all. I too had started to think about it but, with clearance rates of (and this is a technical term), bugger all, I didn't seriously entertain the idea. We'd all read about the horrible side effects and how long the regime was. When I was already experiencing many of these side effects, why would I expose myself to even more illness? It just didn't make sense. So I waited.

As time went by, I was definitely feeling worse. I was so fatigued that my concentration was next to nil and I even stopped driving any distance because I knew I was lacking the awareness and could be a danger to other road users.

Then Pegylated Interferon and Ribavirin became available.This was starting to show good results. I was thinking about it more, although I wasn't eligible at the time because I was co-infected. But, to be honest, there were many things happening around me to sway me away from any treatment. One of the reasons I held back was that Julie and I were finally able to begin IVF after a long struggle to gain access, and because Ribavirin is known to cause severe birth defects, then any chance of pregnancy during treatment had to be avoided.

I think, like with any major commitment, you really have to have your mind in the right place to tackle the task ahead. You have to be ready. Hep C treatment is a major commitment. The timing became right for me in 2005. Suddenly all of the planets had aligned. I had given up work and some difficult situations around me had changed. I was now ready to take on this huge challenge. I had kept hoping that I could enjoy a 'good health year' before I intentionally put myself through the trauma of treatment, but I came to realise that this was never going to happen and I may as well bite the bullet and do it now. We figured if I couldn't cope, then I could always stop, but at least I would've given it a shot. Importantly, not only was I ready, but my wife was too. I cannot emphasise enough how vital the love and support of your loved ones can be. In fact I think it's pivotal.

My infectious diseases hep C specialist advised me I needed 48 weeks of treatment because my genotype was 1b. He explained side effects as well as what the plan was for monitoring my progress. Things such as blood test regimes, what results to hope for, and at what stages. These stages gave me a goal to aim for.

For me it was important to have these goals. A large part of the hep C treatment regime is played between the ears. Before I started I had already been dealing with depression. It is so important to know

your state of mind before beginning hep C therapy. There is a chance of developing depression whilst on treatment, but if you are already aware of your feelings then it makes it much easier to recognise any deteriorating moods and how to deal with things accordingly. There is no shame attached to this and is something the doctors help you closely monitor.

So these goals gave me something tangible to work towards. If it was good news I was encouraged to push on. But I could also 'steel' myself for not so good news. I think it helps to be ready for negative results, but you have to balance your attitude and not talk yourself into a bad frame of mind.

Finally, May 2005, I had picked up my treatment pack. This consisted of a small 'cool bag' to keep the Interferon cool, an instruction manual, and a diary to record anything I felt was appropriate but it also had emergency contact details in the front. There was also a treatment mat, swabs, needles, sharps container and the Interferon and Ribavirin supply. The hep C nurse explained the how-to's, do's and don'ts and assessed that I was confident enough with everything. I guess that's an advantage of having haemophilia and having confidence around injections. At least with the Peg Interferon there wasn't any mixing of powders, it was all pre-mixed in the syringe. Easy as pie.

Those of you unfamiliar with the injection, it is injected just under the skin into the fat, once a week. It is a very fine needle, similar to a diabetic's. To be honest I didn't like it but it really wasn't painful. I guess it was one of those mind games.

Over the next 48 weeks I had those injections and I rotated injection sites. I did it on the same day each week and tried to have it at around the same time. I also took the 5 Ribavirin tablets religiously. Sometimes I had to fight the urge to miss tablets and injections but you push yourself to have the best outcome possible. This is still a battle I fight against my HIV meds.

But I guess the bit you're interested in is what happened during those 48 weeks. After the first injection I did develop redness at the injection site. Whilst not sore at all, it did get a little itchy and remained red at all injection sites throughout the whole deal. My main health really seemed much the same as it was prior to starting, at least for the first 12 weeks.

Then I started to notice my hair falling out - not in huge clumps but more like just extra strands in the shower base, or if I ran my hands through my hair. I was prepared for this and never got too concerned because I was assured this was only short term and my hair would grow back. Of course they were dead right.

Though I was having regular bloods taken to see that my body was coping, and it was nice to know it was, it was the 12 week blood test that would indicate if the therapy was working and whether to continue or not. This was one of those goals I mentioned. I was really anxious about the result, but the news was good. Although the viral load had not disappeared, it had reduced dramatically and suggested we should continue, so I did.

I sort of just plodded along through the weeks, feeling a little flat but generally ok. With about eight weeks to go I started to really feel down. I was starting to get the dreaded flu type symptoms after all and was so tired that I became withdrawn and actually felt apprehensive if I knew I had a social event to attend - even if it was just a family do.

On top of this my white cells were falling and my CD4 counts began to drop. CD4 cells, or T-cells, are what help to fight off infections. This was mainly of concern from the HIV perspective. At this stage there was no need to act but was definitely worth keeping an eye on.

Creeping into the last four weeks, those dodgy blood counts needed to be addressed. The choices were to cease treatment or to have more medications to guard against infections. The trouble was I didn't want more tablets nor did I want to face more injections to boost my white cells. I felt that I was barely just coping as it was. However, I didn't want to stop the hep C treatment as I'd come so close and I didn't want to compromise the end result. So I rolled the dice. I ummed and ahhed long enough to get through to the end. Not exactly a responsible thing to do but I got by with no incident.

So there I was at the end. Julie and I couldn't believe it. I had come close to pulling the pin a couple of times but had managed to ride it out. That on its own was an enormous boost to my pride. There was also a huge sense of relief for both of us. However there was also the anxious wait to see if I had cleared the virus. I had the PCR test done and it came back negative. It was the perfect result. We wanted to shout it from the roof tops but we knew that it may return within six months so we kept a lid on the excitement. Well, sort of.

Within the first month I was feeling great. All of my blood counts had returned to normal and I got a bit of energy back. I started walking as often as my joints would allow and gained some fitness. I was starting to feel like the clock had been turned back a dozen years. All of the jobs around the house that had been put off were getting done. In fact I had so many things on the go that my energy was freaking Julie out! I don't know if this was a normal result but it sure felt good.

Another brilliant bonus is my nausea levels have dropped almost completely, I'm not as rashy and itchy, and my skin looks healthier in general. I guess my liver is just processing everything so much better.

If I could pick one negative then it would be that my increased energy levels are having a direct impact on my joints and how many bleeds I'm having, but I reckon that's a pretty good trade-off. I will admit that I have come back to earth with some fatigue but I just have to realise that I'm still dealing with haemophilia and HIV and yes I'm getting old too.

In summing up I can only say it has been worth the struggle. I have been very lucky over the years in terms of responding to many of my meds, and I've been lucky again this time.

So the word success is becoming relevant in hep C therapy. Success rates can be 50% upwards. I really hope to encourage people to seek treatment. It isn't easy but it's almost harder to make the decision to start. There is no reason why you can't be one of those 50% who, like me, have cleared the Hep C virus successfully.

Three presentations in the Hepatitis C Treatment and Care stream at the Conference are reported on below by Rob Christie (WFH Vice President – Finance) and Suzanne O'Callaghan (HFA Policy Officer).

HEPATITIS C TREATMENT AND CARE

Rob Christie and Suzanne O'Callaghan

Neil Boal – Positively Negative

Neil Boal's presentation was an account of his personal journey through hepatitis C treatment. Neil has been actively involved in speaking publicly about the issues for people with bleeding disorders who are affected by hepatitis C and HIV. His presentation was an excellent introduction for the two following presentations, highlighting the questions about treatment that are important in the everyday lives of people with bleeding disorders, and using deft humour to bring the realities home.

The full text of Neil's presentation is published in this issue of *National Haemophilia*.

Neil finished his presentation by launching the HFA Hepatitis C Needs Assessment Report, "*A double whammy*". The Report considers the needs and priorities of the bleeding disorders community affected by hepatitis C and contains excerpts from many personal stories.

Professor Geoffrey Farrell - Hepatitis C treatment and care: relevance to haemophilia

Professor Geoff Farrell is Professor of Hepatic Medicine and Gastroenterology at The Canberra Hospital and a recognised expert in hepatitis C medicine. He was able to draw on his many years' experience of providing medical care to people with hepatitis C to cover the key issues on treatment and care for people with bleeding disorders in a very accessible way.

He began with a discussion of the physical and lifestyle factors that can have an impact on hepatitis C. His comments about alcohol intake caused some surprise and a great deal of interest among the audience. Contrary to previous advice, he reported that light alcohol use is now not thought to make liver disease worse with hepatitis C. However, the risk of cirrhosis and liver cancer increases with heavy drinking over a lifetime. He also recommended that people curb alcohol dependence before antiviral treatment and drink cautiously during treatment. He drew attention to the metabolic issues that come into play with hepatitis C: steatosis (fatty liver) has a direct effect on the virus in genotypes 2 and 3 and obesity and type 2 diabetes reduce the response to treatment. Alcohol can contribute to steatosis. Smoking also increases the risk of fibrosis.

Professor Farrell also gave an update on hepatitis C treatment. He pointed out that having haemophilia did not change the medical reasons to consider treatment. However, patients are advised to have treatment before they turn 60 and preferably by their 30s or 40s as the younger you have treatment, the more likely you are to have a better result. The target end result of antiviral treatment is a Sustained Viral Response (SVR) where levels of hepatitis C virus in the blood are undetectable for six months after treatment. Long term studies show there are very few people who relapse after this point, so medical researchers are now more confident that an SVR is a "cure" for hepatitis C. Recommended treatment courses are 24 weeks for genotypes 2 and 3 (SVR 70-90%) and 48 weeks for genotypes 1 and 4 (SVR 40-50%).

Treatment is now more individualised. Medication doses can be altered during treatment to manage side-effects and help the patient to finish the treatment. During treatment, the patient is also checked to see if they are likely to have a response to treatment and if the length of treatment should be shortened. If patients have a good response at four weeks, they will be given six months' treatment. If there is no response at 12 weeks, treatment will be discontinued as the patient is not likely to clear the virus. Patients may also be prescribed anti-depressants to manage depression during treatment.

New combination treatments are currently being trialled. It is likely that pegylated interferon and ribavirin will be the standard of care for the next three years at least and that pegylated interferon will be part of a hepatitis C treatment regime for the next five to seven years.

Professor Farrell finished with some suggestions about self care for people with hepatitis C:

- Avoid excessive alcohol consumption
- Exercise daily to avoid being overweight and risks for type 2 diabetes
- Quit smoking
- Vaccinate against other forms of hepatitis
- Work on a positive attitude and healthy lifestyle

Dr Stephen McNally – Making decisions about hepatitis C treatment: What men are thinking

Even today only around 1% of people in the wider population with hepatitis C have treatment every year. This is in spite of better results with hepatitis C combination therapy and wider eligibility for government subsidised treatment now that a liver biopsy is no longer required. Stephen McNally reported on a study in Victoria by the Australian Research Centre in Sex, Health and Society (ARCSHS) of 224 people with hepatitis C and a number of GPs and medical specialists. The study looked at decision-making

about treatment and some of the barriers to accessing treatment.

In the study men were more likely than women to be currently on treatment, and those who had been diagnosed in the last five years were more likely to be receiving treatment currently than those who were diagnosed more than five years ago.

A number of factors were barriers to taking up antiviral therapy:

- Concerns about the effectiveness of treatment
- Side-effects, including depression
- The impact on family, work and relationships
- If the person's current liver status is good or they are feeling very well
- Their relationship with their GP or specialist
- The costs of travelling, not working and managing side-effects

Treatment decisions were not straightforward. Side-effects could be debilitating with no guarantee of success, and there could be a considerable time commitment to liver clinic follow-up. This is a significant problem when some 46% of respondents rated their health as poor. Interestingly, it was only after they started treatment that men were more likely to think it was important to have a supportive partner and a good relationship with their doctor.

Peter Mathews is HFA Vice President, and Executive Officer of Haemophilia Foundation New South Wales. The following is from a presentation given at the Canberra Conference.

THE COMPLEXITY OF LIVING WITH HAEMOPHILIA

Peter Mathews

I am often asked "how do you cope with your haemophilia?", referring to bleeding episodes, to which I usually answer "without much trouble". When I talk with other older people living with haemophilia they usually have a similar response. Treatment these days, with recombinant products, takes as little as 10 minutes, which is nothing compared to the days when fresh frozen plasma and cryoprecipitate were used to treat a bleed, which took 1-3 hours, (but I will finish with the "young people these days have no idea how easy ……." type talk right here!).

But living with haemophilia doesn't stop when the needle is pulled out of the vein.

What are the complexities of living with haemophilia? First on my list has to be joint damage and arthritis. Once the joint has been damaged by bleeding episodes it cannot be stopped and the pain from a damaged joint can be just as bad as the pain from a bleed. Depending on the severity of the joint damage it can prevent you from getting out of the house, going to work, it stops you from doing those normal around the house type jobs that you used to be able to do and it might even stop you getting out of bed in the morning. Chronic pain can take over your life.

What about pain relief for chronic pain? The area of medicine which deals with chronic pain is a specialist field in itself. But there is no simple answer to chronic pain - there is no one drug that will allow you to go back to the quality of life you had before. Again, from speaking with other people with haemophilia, the biggest problem in pain management is the use of narcotics. Before narcotics are even considered, all manner of medications will have been tried. No one will deny that stronger pain relief is required. However, once started, narcotics introduce a whole manner of other issues; the first is becoming dependant on these types of drugs.

Doctors in the field of pain management have two main concerns when people start to become dependent on narcotics - narcotics may stop people from living a close to normal lifestyle as they can result in lethargy and loss of motivation. On the other hand, however, chronic pain stops us living a close to normal life and loss of motivation, so we are left in a conundrum. In addition, if a person has built up a high tolerance to narcotics, which happens quite quickly, and then is badly injured or has one of those horrendously painful bleeds, the doctors may not be able to manage the pain within the limits that apply to the use of narcotics. As such, pain relief continues to be a difficult area.

The next question which arises for someone who has chronic joint damage is should the joint be replaced with an artificial one? But when is the right time to have the joint replaced? Not too early, because artificial joints do not have a life time warranty, but not too late as the surrounding bone, tendons, ligaments etc may have deteriorated to a point where it is impossible to fit an artificial joint.

There are also a whole range of non-medical considerations that have to be considered. As it takes some time before you are fully rehabilitated, have I accrued enough leave to cover this time away from work, how will taking a few months leave affect career, plans to save for a house, plans to have children, all the way down to - can I live on one wage, or no wage at all? Questions such as these have to be considered and answered.

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Blood borne viruses brought many new complexities to the lives of those living with haemophilia. HIV/AIDS came out of nowhere and struck the haemophilia community a huge blow. I was not infected with HIV and will not pretend to understand the issues which those who were infected have to deal with on a day-to-day basis. All I can say is that those with HIV/AIDS remain high on the priority list as far as HFNSW, HFA and I are concerned and will not be forgotten or pushed aside as the numbers of those infected decrease over time.

I was infected with hepatitis C, so I am able to offer some insight as to the complications which this has brought to the lives of those with haemophilia. Lethargy, mental fatigue, portal hypertension are just some of the symptoms of liver disease. Give those types of symptoms to a "normal" person and they will struggle to cope, let alone dealing with haemophilia as well. There are drug therapies available to try and clear the virus, however, the side effects can be very debilitating and last, in general, for 48 weeks. At the end of those 48 weeks there is no guarantee that the treatment has worked and you could be back at square one.

And again, there are all those issues listed earlier which have to be considered, as to the right time to have hep C therapy. Will I be able to work while I am having treatment therapy, if not do I have enough sick leave, how will I afford to live, how will my family afford to live, impact on my career, affect plans to buy a house, have children? …… and so the list goes on again!

There are also those whose hep C infection has caused cirrhosis of the liver, which has advanced to a point where standard hep C treatment is not an option – their only option being a liver transplant. All the medical and non-medical issues surrounding this issue are enormous and we are only now coming to grips with this.

The issues listed above are just some of the considerations that have to be worked through when you live with haemophilia. This list is far from exhaustive – there are numerous other issues which affect people with haemophilia.

Having said all that, I believe that people with haemophilia are a unique group of individuals who have the ability to adjust to whatever situation they may find themselves in – being able to use your left hand because you have a right elbow bleed, learning to drive a car with your left foot instead of your right because of joint damage, balancing a cup of coffee in one hand while using a crutch in the other – and not spill a drop!

It was once said to me that people with haemophilia seem to be of high intelligence. Educational statistics and common sense tell us that this cannot be so. I believe that what was labelled as intelligence is in fact ingenuity to adapt, adjust and persevere with whatever life throws at us. These are the skills that we, people living with haemophilia, utilise to survive and deal with the challenges of living with haemophilia, as well as ageing. And, we do it very well.

CSL BIOPLASMA / DAWN THORP HAEMOPHILIA NURSES' TRAVEL GRANT

The Dawn Thorp Haemophilia Nurses' Travel Grant is open – travels grants are available to Australian and NZ nurses. Nurses should contact michael.grant@csl.com.au for details. Applications close 28 March 2008.

CONFERENCE OPENING

Gavin Finkelstein, President of HFA, and Deon York, President of HFNZ, acknowledged the work of Haemophilia Foundation Australia (HFA) staff and volunteers and the Conference Program Committee chaired by Dr Scott Dunkley, which developed an exciting multidisciplinary conference program. The committee included health professionals and community representatives from Australia and New Zealand.

They also acknowledged the National Patron, Sir Ninian Stephen, who has had a long interest in the bleeding disorders community and has helped to shape some of the major developments in the sector.

In his opening address Deon York noted the theme of the Conference was "Achieving success to last a lifetime". He noted the lifetime of a person with haemophilia or a related bleeding disorder had been much shorter in the past. We have now reached a stage where, thanks to advances in medical care, the life expectancy of a person with haemophilia virtually equates with the general population. Ageing brings additional challenges to a lifelong chronic disorder. Now there is a truly aging population, it is appropriate that the Conference program has sessions that range from childhood and youth matters right up to the complications that ageing bring.

Deon York also noted that success too was measured differently in the past. What success means now in terms of the treatment and care of people with haemophilia, advances in medical knowledge and clinical research as well as daily clinical practice has certainly shifted. He noted that success that lasts a lifetime also has a lot to do with the foundations that are put down for the next generation and requires discussions about primary prophylaxis, overcoming inhibitors, ensuring continual adequate safety and supply of factor replacement therapies, growing healthy children, families and communities.

Peter Fogarty is HFA Treasurer and a Committee Member of Haemophilia Foundation Queensland.

THE HARD QUESTIONS

Peter Fogarty

At what point can we no longer afford ourselves? Factor VIII use has increased exponentially. Studies have clearly shown the comprehensive care model as the gold standard of care, but many people in our community have had such a model of care for a number of years. The expenditure keeps rising, but at what cost to individual health care outcomes? The Malmo, Sweden, treatment regime has long led the world in levels of individual factor use, whilst the Dutch protocol comes in a little lower. Many of the younger generation in Australia find themselves on levels that rival the Malmo protocol for prophylaxis and at some point the questions may be asked.

Speaking at the 14th Australian & New Zealand Haemophilia Conference, Dr Ian Kerridge, challenged us all in the opening plenary to ask the hard questions about our own standard of treatment and care. As with many things there is a law of diminishing returns. Many of our younger community are doing well and engaging in activities that the older generation could only dream of. So what cost do we put as a community on achieving the last measures of success? Dr Kerridge reminded us that 18 million people die prematurely each year from preventable diseases in the third world. When put in that context, what price do we pay for small incremental improvements in the quality of care in the western world?

Dr Kerridge's talk was about 'Ethnomics' a word he claims to have invented blending Ethics and Economics. It is about asking the hard ethical questions while doing ane economic analysis of health care budgeting and service delivery. Can this money be better spent? I am sure that as an individual patient or parent, the answer is probably 'no, what better use for the money is there than my (or my child's) health?' It is difficult to rationalise the economics when there is a personal face on it, and even harder if it is your own face. One of the joys of ethics is that there is no requirement to provide answers. Ethics is about asking the hard questions, provoking discussion and looking for ways to increase people's awareness of the alternatives.There is no hard and fast point at which money should no longer be spent on haemophilia care and treatment. A proposal to stop all education spending, all environment spending, all other medical expenditure, all roads and infrastructure spending, to focus entirely on finding a 'cure' for haemophilia would no doubt be shouted down in the public arena before the sentence had finished being read out. So where then is the tipping point, at what point will the public medical debate shift from haemophilia as a sustainable funded condition to one that places undue strain on the public purse? And when that tipping point is reached, how will we as a community react? Will we be prepared? Will we all be involved in strong and vibrant foundations ready to mobilise and protect what we have?

Ann Roberts is President of Haemophilia Foundation Victoria and Delegate to HFA Council.

HFA COUNCIL MEETING

Ann Roberts

The HFA conference was, as usual, a hot spot for meeting with people with bleeding disorders and the health professionals who look after them, as well as others including government officials and treatment product producers. The conference is unique to the haemophilia community and everyone present shares the common goal of seeking ways to benefit and improve the lives of people living with bleeding disorders.

There was an amazing variety of sessions with a wide range of choices - from older people to parents with a newly diagnosed child. Issues included available treatments for hepatitis C, management and care for von Willebrand disorder, and issues concerning youth. Even after having attended numerous conferences, I still found it interesting to attend and learn of constantly improving and changing treatments and new ideas for programs and workshops, and to meet health professionals new to the community and of course, to catch up with interstate friends and those from New Zealand.

Another important part of my trip to Canberra was to attend the Annual HFA Council Meeting which was held immediately after the Conference.

The HFA Council established the policy direction of HFA and consists of haemophilia foundation delegates from all around Australia except NT. Council is made up of one delegate each from Tasmania and ACT, and two delegates each from Western Australia, South Australia, Victoria, New South Wales and Queensland. The delegates represent their local haemophilia foundation on Council. The delegates keep in touch with HFA activities and are required to make decisions on policy throughout the year. They receive regular communications from HFA and provide regular feedback to their foundation. They must ensure a cross flow of information to and from their local management committee and HFA. As the voting member at Council for their foundation they are expected to be on top of the issues under discussion so they can participate actively and vote on behalf of their foundation.

This year's agenda included reports from sub-committees of HFA:

Education and Resources - looking at new educational and information materials to keep abreast of change.

International Relationships – including relationships with World Federation of Hemophilia and planning and reviewing HFA's twinning with Thailand.

Fundraising and Communications - the Development Manager's report included information on funds available for State activities such as camps and support groups etc, Haemophilia Awareness Week and Global Feast activities.

Governance – implications of the recent changes to HFA constitution.

Council also considered reports from each State/Territory Foundation, publications and communication, including *National Haemophilia* newsletter and the HFA web site. Special Purpose Funds and Awards, including Damon Courtenay Memorial Endowment Fund, Haemophilia Foundation Research Fund and the inaugural Vision and Leadership Awards were also discussed.

A relatively new initiative is for the Youth Committee to have an observer at Council and for a report to be tabled by a representative of the Youth Council. Robert McCabe, Co-Chair of the Youth Council presented a report to update on the Youth Committee's year of activities.

The agenda included a discussion on planning for the next national conference to be held in Brisbane, 8-11 October 2009 and the World Federation of Hemophilia Congress in Istanbul, Turkey, 1-5 June 2008.

Several important issues affecting the bleeding disorders were discussed ranging from the supply and safety of treatment products and the impact of blood borne viruses to specific issues affecting women, the ageing, people with von Willebrand disorder, and for children transitioning to adult care settings. A workshop during the Council meeting focussed on hepatitis C and the impact on the community.

So as you can see, after the busy schedule at the conference many went home inspired, while others stayed on for a day and a half to talk about what is happening at the local and national foundation levels and what decisions and plans need to be made to help improve the lives of people with bleeding disorders. It is a busy, but productive time for our community.

Issues included available treatments for hepatitis C, management and care for von Willebrand disorder, and issues concerning youth.

Suzanne O'Callaghan is HFA Policy Officer.

WHAT IS HFA DOING ABOUT HEPATITIS C?

Suzanne O'Callaghan

The last few months have been an exciting time where some key elements of HFA's hepatitis C strategy have been completed.

'DOUBLE WHAMMY' REPORT

People with bleeding disorders who were exposed to hepatitis C through the blood supply have now been living with the impact of hepatitis C for more than 20 years. As we have reported previously, HFA felt it was important to have a good understanding of community needs and has undertaken a comprehensive needs assessment, consulting with people with bleeding disorders, state and territory Haemophilia Foundations, health professionals and other community organizations about the current issues relating to hepatitis C.

The 'Double Whammy' report is the result of that consultation. As you can imagine, people in the community had diverse experiences of hepatitis C. The report explores the evidence about community needs and gives recommendations for future action. Many thanks to all those who contributed.

A copy of the report is enclosed with this issue of National Haemophilia. To reach as many members as possible, both HFA and state and territory Foundations are sending out copies of the report to members. This is also to make sure that wherever possible members receive a copy automatically rather than having to identify themselves to request a copy. For privacy reasons HFA cannot have access to state and territory Foundation mailing lists, so some duplication may occur. If you receive two copies of the report and don't need both, please consider passing one on to someone else or returning a copy to your Haemophilia Foundation or Haemophilia Centre.

We hope you will find the time to read the report, particularly the personal stories of people in the focus groups and those who completed the HFA hepatitis C survey in 2003. It was important to give the evidence about community needs in people's own words. In the report people's quotes are highlighted in shaded sections and give a powerful account of the impact of hepatitis C on the bleeding disorders community. The report is organised under headings by the subjects people discussed. These are outlined in the table of contents and you may prefer to use the table of contents to dip into one section at a time, according to the topics that interest you.

REPORT FEEDBACK

You will notice that there is a feedback form with the report. HFA is keen to have your response to the report. Do you feel it has covered the range of experiences and needs of people in the bleeding disorders community, or are there other issues that need to be added? Is there anything else you want to say about the report or hepatitis C? Please take this opportunity to give your feedback. You can complete the printed form and send it back to HFA or complete the online form at www.haemophilia.org.au and email it to HFA at hfaust@haemophilia.org.au. Your comments will assist with the direction of HFA's work on hepatitis C.

HFA HEPATITIS C WORKING PARTY

You may be wondering what happens next now that the report has been released. At the HFA Council meeting in October 2007, Delegates looked more closely at how to follow up the report. A number of Council Delegates volunteered to form the HFA Hepatitis C Working Party and prepare strategies to implement the recommendations in the report. Strategies will include collaborations with other groups as well, particularly health care professionals. So far there have been two meetings of the Working Party by teleconference with another planned before the end of the year. HFA is reassessing and implementing the recommendations as soon as is feasible and will keep you up-to-date with developments.

HAEMOPHILIA CONFERENCE

One of the outcomes of consultation for the HFA needs assessment report was to highlight key needs for hepatitis C information and education for the bleeding disorders community. The 14th Australian and New Zealand Haemophilia Conference in October 2007 provided a great opportunity to provide education on some areas for both health professionals and the community.

Key issues were built into the Conference program and included:

- The latest on hepatitis C treatment
- Disclosure and relationships
- Stigma and discrimination
- Depression
- Transition into adulthood
- Other people's experiences

It was time also to release the HFA needs assessment ('A Double Whammy') report. Thanks to a huge effort by participants in the focus groups who responded with their feedback and the haemophilia social workers/counsellors co-ordinating

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the feedback, the HFA Board and some members of the HFA Hepatitis C Advisory Group, who reviewed the report, the HFA team, the designer and the printer who got the finished product to the Conference, all in a very timely fashion, the report was ready for release and a copy given to all who attended the conference and all health professionals who attended the health professional meetings. Participants in the focus groups were sent their copies ahead of the release.

Neil Boal, formerly President of HFV and a very active public speaker on living with hepatitis C and a bleeding disorder, launched the report with a very eloquent account of his experiences. His presentation is printed in this issue of *National Haemophilia*. I also gave a presentation on the results and recommendations in the report.

This was my first Haemophilia Conference and I was very interested to see how many people from the community participated actively. For me, in comparison to other health-related conferences, the impact on the conference was noticeable: there seemed to be a very pragmatic approach in presentations and a focus on the "real life" meaning of medical and scientific research. It was also great to see the involvement of younger members in the sessions - this gave a fresh perspective to the discussion.

NATIONAL SYMPOSIUM ON HEPATITIS B AND C

In the needs assessment consultation it became clear that state and territory Haemophilia Foundations and health professionals were concerned that some people with bleeding disorders may not be aware of the need to monitor their hepatitis C. The National Symposium on Hepatitis B and C, held at St. Vincent's Hospital in Melbourne in November 2007, was an opportunity to bring this and other needs of the bleeding disorders community around hepatitis C to the attention of hepatitis C specialists and GPs from around Australia. HFA submitted a poster for the Symposium and the abstract was included in the Symposium Notes. The poster gave rise to discussions with other health agencies about future collaborations for GP and community education.

Dr Stuart Roberts is Director of Gastroenterology & Hepatology at The Alfred Hospital, Victoria. The following article was published in the November 2007 Newsletter of Haemophilia Foundation Victoria.

HEPATITIS C THERAPY

What's new and on the horizon?

Dr Stuart Roberts

Significant advances have been made in the therapy of hepatitis C in recent times. While combination peg Interferon alpha-2 plus Ribavirin remains the standard of care (treatment), there has been a greater understanding of the role of a rapid and early virologic response in predicting better outcomes and the potential for altering duration of therapy for patients with different HCV genotype infections. The potential exists for shortening treatment duration for those with genotype 1, down to 24 weeks in those who respond rapidly to therapy by week 4, while for some patients who respond more slowly to therapy a longer duration of treatment up to 72 weeks may be indicated. For those with genotype 2 and 3 infection, the results of the Accelerate study that explored the role of a shortened treatment duration of 16 weeks showed unequivocally that 24 weeks was needed to optimise long-term clearance of the virus.

There are several promising treatments for hepatitis C on the horizon including a range of small, orally taken molecules that inhibit key enzymes of the virus that it needs for viral replication. These include the protease inhibitors of which Telaprevir is the most forward in clinical trials, and the hepatitis C polymerase inhibitors of which the most promising appears to be the Roche compound R1626. While both classes of drugs are potent inhibitors of hepatitis C, they are unlikely to be useful as single therapy due to problems of viral resistance and lack of long term clearance of the virus. However, in combination with peg Interferon alpha-2 with or without Ribavirin, the potential exists for enhancing the sustained viral response.

Both Telaprevir and R1626 are in phase II clinical studies to determine optimal regimes to move forward into larger scale clinical trials. There is therefore much to look forward to over the next five years in trying to improve the outcomes of treatment of patients with chronic hepatitis C.

Maureen Spilsbury is Senior Haemophilia Social Worker at the Queensland Haemophilia Centre, and a member of Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group.

AUSTRALIA/NZ HAEMOPHILIA SOCIAL WORKERS' AND COUNSELLORS' GROUP MEETS IN CANBERRA

Maureen Spilsbury

As in past years, members of the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group (ANZHSWCG) met the day before the recent Haemophilia Conference. We greatly appreciate the opportunity to meet face-to-face as the majority of our contact through the year is by email or phone. The group is made up of workers who provide psychosocial support to adults and/or children in the haemophilia community. In reality, we come from a wide range of work roles and position titles including "social worker", "counsellor" and "outreach worker". The positions are also unique in their role and mandate in each haemophilia community. While some of the positions are full-time and dedicated to haemophilia alone, others are part-time and those workers will also have responsibility to haematology, oncology, other hospital departments or haemophilia foundations. Some workers attend regular haemophilia clinics with a multidisciplinary focus and others work primarily outside of the health system, while some work across both community and health settings. Over the years the group has evolved into a strong and supportive network with members readily sharing their expert knowledge, skill and resources with each other. Unfortunately there are a couple of Australian states where there is no funded or dedicated psychosocial support service to the haemophilia community. Current membership includes counsellors from VIC, QLD, NSW, WA and NZ, however currently there is no counsellor representative from SA or Tasmania.

The group would like to wholeheartedly thank outgoing chairperson, Sandy Breit (VIC), for her commitment to guiding our group over the past two years. Sandy has done a wonderful job of organising our meetings, maintaining a link between all of the group members and also between the group and HFA. We are grateful for her sensitive and enlightened leadership. We are also grateful that Sharon Hawkins (WA) kindly and capably stepped into the chairperson's role during Sandy's long service leave. Sandy and Sharon more recently, co-chaired the group until our recent meeting. Incoming co-chairs are Leonie Mudge (NSW) and Kelly Brady (QLD). We congratulate them on their unanimous election and look forward to working with them both. We welcomed first time attendees, Bronwyn Wigg (VIC) and Kate Lenthen (NSW) who are both social workers in paediatric centres.

Some of the issues the group routinely has on our agenda include:

- A feedback time from each member, providing an overview of their work in the preceding year. This is a valuable opportunity to hear of the creative psychosocial work which is being done across the states and countries
- A discussion on trends and issues relating to blood borne viruses
- Feedback and resource sharing from workshop, conference and congress attendance
- Information sharing about Centrelink related issues and changes; including Health Care Card, Carer Allowance and Carer Payment and other payments
- Community needs regarding education and work
- Superannuation and insurance
- Issues relating to new diagnoses
- Dealing with progressing illnesses and deaths
- The impact of aging on the community
- Travel
- Discrimination
- Issues relating to financial disadvantage
- Mental health and quality of life issues
- Issues related to housing

Some of the more specific psychosocial issues discussed during the Canberra meeting included:

- The gaps in nursing home care for people with haemophilia including those who are younger
- The need to provide relevant service and support to those affected by blood borne viruses
- Feedback from those involved in the HFA Hepatitis C focus groups
- Information sharing from workers who attended the Hepatitis Australia Hepatitis C Educators' Conference

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- Decreasing mobility and the gaps and difficulties regarding provision of medical aids and home modifications
- Utilising Disability Apprenticeships
- Difficulty of community members being able to access dental services and associated costs
- How best to support those from the community who have inhibitors

The varieties of psychosocial programs facilitated/supported by workers and offered in some states or across the two countries include:

- New family meetings and camps
- Family morning teas associated with haemophilia clinics
- Transition from paediatric to adult health system programs
- Regular parent/family discussion groups
- Parent carer group
- Partners' group
- Women who carry the haemophilia gene group
- Boys' Days program
- Siblings' Day
- Men's Breakfast
- Education sessions
- Proposed couples' weekend
- Weekend away for those affected by HIV
- Offering specific sessions relating to psychosocial issues at Haemophilia Foundation camps
- Young women's weekend workshop
- Men's dinners
- Children's workshops

Following on from Kelly Brady's article about PEP, watch out for news of Parents Empowering Parents coming to an area near you! Ask your social worker, counsellor, outreach worker or nurse about it.

During the day Sharon Caris (HFA Executive Director) and Suzanne O'Callaghan (HFA Policy Officer) attended our meeting to get feedback from the group about trends and concerns and to gather information about emerging psychosocial issues. They were also able to provide us with updates about HFA projects, resources and the newly written HFA National Hepatitis C Needs Assessment Report.

Our group aims to contribute an article about psychosocial issues related to haemophilia to each addition of *National Haemophilia.* Let us know if you would like us to write an article about any particular psychosocial issue. Chances are others would be interested to read it as well.

The ANZHSWCG is grateful to the HFA for their ongoing support and for the fact that they facilitate the opportunity for us to have contact with each other and to attend the National Conferences.

NATIONAL HAEMOPHILIA FOUNDATION RAFFLE

The raffle was drawn on Wednesday 31 October at 1624 High St Glen Iris VIC at 4pm (ESST).

Results were:

1st PRIZE ~ Crown Melbourne Package RRP $730.00

Overnight accommodation at the Crown Promenade with breakfast for two people and valet parking, $150 voucher at Breezes and a $250 travel voucher. Accommodation & meals kindly donated by Crown Melbourne

WINNER: M Durson Ticket No: 2188

2nd PRIZE ~ $500 Harvey Norman Voucher

Kindly donated by Harvey Norman

WINNER: T Lamb Ticket No: 4281

3rd PRIZE ~ Prince of Wales Hotel Package RRP $350.00

Overnight accommodation at the Prince of Wales Hotel, St Kilda Melbourne with breakfast for two people. Kindly donated by Juanita Scott Travel

WINNER: D Spencer Ticket No: 0253

4th PRIZE ~ Handmade Quillow RRP $350.00

A beautiful handmade quillow. A quilt that can be converted into a pillow - donated by HFACT and made by volunteer crafts people from the Canberra region

WINNER: D & P Scolaro Ticket No: 4205

5th PRIZE ~ $50 I-Subscribe Voucher and $50 Coles/Myer Gift Card

Voucher kindly donated by I-Subscribe

WINNER: N Steele Ticket No: 4664

ACT Permit No ACT R 07/00169 (permits not required in other states where tickets are for sale)

DAMON COURTENAY MEMORIAL ENDOWMENT FUND

Grant Applications 2008

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

A distribution of approximately $15,000 is to be made in 2008.

Applications are invited from individuals with haemophilia or von Willebrand disorder and other coagulation disorders. Family members or representatives of recognised haemophilia organisations may make applications on behalf of individuals. Applicants must reside in Australia.

Applications will be considered in accordance with the following conditions of the Trust:

"Income from the Fund can be distributed for the purposes of providing care, treatment, education and welfare for people with haemophilia and/or the families of such persons and/or other such matters related thereto including public education programs and other activities undertaken by HFA and its associated organisations in Australia."

Applications must be made on the prescribed application form which may be requested from Haemophilia Foundation Australia, 1624 High Street, Glen Iris, Victoria 3146, or by telephoning HFA on 1800 807 173, or email on hfaust@haemophilia.org.au or can be completed on line at www.haemophilia.org.au.

Closing date for 2008 submissions is 31 March 2008.

Helen Starosta is Co-Chair of the Australian Haemophilia Nurses' Group.

ICE AND MEDICAL ALERT DEVICES

Helen Starosta

What would happen if you were in an emergency situation and unable to communicate that you had a significant medical condition such as haemophilia or von Willebrand Disorder?

If you are involved in an accident, ambulance/emergency personnel will examine you and attempt to find information on you that will alert them to your medical condition.

There are a number of possible ways that this information could be communicated to medical personnel who may need to know about your condition:

- Your treatment centre provides a wallet sized treatment card which provides medical information.
- A medical alert device such as a bracelet or necklace.
- ICE (IN CASE OF EMERGENCY) on your mobile phone to talk to your next-of-kin or significant carer.

Please discuss and seek advice from your Haemophilia Treatment Centre about the suitability of these options.

MEDICAL ALERT BRACELET OR NECKLACE

A medical alert device worn on your person can alert medical personnel to your medical condition. Wearing one is the most important factor. There are a number of options for medical alert devices, and a range of attractive options for adults and children can be found on the Internet.

In Australia you can sign up for the medical alert service at www.medicalert.com.au/.This option is subsidised by some State/Territory Haemophilia Foundations and provides a good service.

However, a device that simply states your medical condition with next-of-kin contact details and/or the name of your Treatment Centre may also be acceptable. An example of acceptable medical alert devices can be found at http://www.n-styleid.com/. The devices on this website have the medically recognised symbol for a significant medical condition and space where the medical condition and other information can be engraved. The website displays a variety of styles that are reasonably priced and delivery from overseas is reliable.

If you use an Internet search engine such as Google, you may find other styles that you or your child are happy to wear. This is the most important factor of any medical alert device.

ICE – IN CASE OF EMERGENCY

ICE (In Case of Emergency) telephone numbers in your mobile phone address book are another way to alert emergency services to the people you want them to contact in an emergency. Enter "ICE" and the most appropriate contact phone number for an emergency into your phone's address book. You can have more than one ICE contact if you choose, eg you could use ICE1, ICE2, ICE Karen, ICE John, ICE Wife, ICE Mother, ICE Father etc. Do not use your Haemophilia Treatment Centre phone number as this number may be unattended outside of office hours. If the emergency services need to contact someone on your behalf in an emergency, they can check your mobile phone address book and contact the people listed.

The ICE contact should be told that they have been nominated. It is important that you choose the ICE contact carefully, especially if they are required to give consent for emergency medical treatment. Remember to update ICE contact phone numbers if they change.

There are some potential problems with ICE to consider before you use it as a tool for emergency communication:

- Information could become out-of-date, eg if the designated next-of-kin number has been disconnected or you change your next-of-kin altogether. Worst-case scenario – you don't want them to call the ex.
- Some mobile phones don't necessarily provide any direct means of identifying their owner.
- The phone could be damaged to the point that information stored in it is no longer retrievable.
- A lot of people secure their phones with PINs to prevent unauthorised use, a factor that could conceivably block any attempts by emergency personnel to retrieve information from them.

However, despite the possible pitfalls, this could be a useful way of contacting next-of-kin.

Promotion of ICE on mobile phones in Australia was taken up by Telstra after Florenz Ronn's article "ICE – in case of emergency", was published in the Melbourne newspaper, *The Age*, on 28 July 2005. On 1 August 2005 *The Age* reported that Telstra's Consumer and Marketing Group Managing Director, David Moffatt, had said Telstra will send an SMS message to more than seven million of its mobile customers and post information on its website at telstra.com to raise consumer awareness of ICE on mobile phones. Telstra's information about ICE can be found at: http://www.telstra.com.au/abouttelstra/advice/mobile/ice.cfm.

HOW DOES ICE WORK?

Simply enter the acronym ICE – for In Case of Emergency – into your mobile's address book and list the name and number of the person you want to be contacted in an emergency. It could be a family member, close friend or even your doctor.

You could also store your blood type and other relevant information under your ICE entry in the handsets that allow notes in the contacts section.

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Associate Professor John Lloyd was the recipient of the Ron Sawers Award at the Conference Gala Dinner in October.

ASSOCIATE PROFESSOR JOHN LLOYD RECEIVES THE RON SAWERS AWARD IN CANBERRA

Dr Ron Sawers

The Award is named after Dr Ron Sawers who initiated the development and maintenance of high standards of haemophilia care throughout his 40 years of dedicated service at the Alfred Hospital in Melbourne.
Dr Sawers retired from the hospital in 1985. He still attends the Haemophilia Foundation Victoria Christmas lunch and is a much loved identity in the world of haemophilia care.

Dr Sawers recognised the need for patients and their families to receive support and encouraged the development of patient support groups. These patient support groups became a strong component of the development of high standards of treatment and care in this country, and the forerunner of bleeding disorders patient advocacy. Dr Sawers passionately supported the improvement of standards of treatment to help patients to manage their condition, and took care of generations of families who were affected by haemophilia and related bleeding disorders. The Ronald Sawers Haemophilia Centre at the Alfred Hospital, now under the leadership of Associate Professor Alison Street, has become internationally recognised as a centre for excellence.

The Ron Sawers Award may be given by HFA to a doctor or scientist who has made a significant contribution towards improving quality of life for people with haemophilia through significant research or providing clinical care of the highest standard to people with bleeding disorders.

A/Prof John Lloyd

The nomination from Haemophilia Foundation South Australia for Associate Professor John Lloyd to receive the Award received wholehearted support from Haemophilia Foundation Australia Council and the Australian Haemophilia Centre Directors' Organisation.

This is a very worthy award and recognition of Associate Professor Lloyd's commitment and dedication to the clinical needs and welfare of people with haemophilia and related bleeding disorders, and his major contribution to the medical and scientific developments which have enhanced the quality of care and treatment of haemophilia in Australia over a period of more than 40 years.

Associate Professor Lloyd recently retired as Senior Specialist Haematologist in the Division of Haematology at the Institute of Medical and Veterinary Science in Adelaide. He was an inaugural member of the HFA Medical Advisory Panel in 1988 and the first Chairman of the Australian Haemophilia Centre Directors' Organisation when it separated from HFA and became incorporated in 2001.

His CV is twenty pages long and includes 50 publications and 40 Abstracts. He has been a Committee Member of Haemophilia Foundation South Australia, and a member of the ARCBS Coagulation Factor Users Group in South Australia, as well as many other State and national blood committees.

Several of his AHCDO colleagues have commented that he is always a willing adviser to those with difficult clinical problems and many of his patients have commented on how approachable and concerned he has always been for them.

The Canberra conference was a fitting place for the Award to be presented as Associate Professor Lloyd was amongst his peers and patients.

continued from page 17

HOW COULD ICE HELP?

Having ICE in your mobile phone may make it quicker and easier for emergency services workers or passers-by to get in contact with someone you want who can help with vital information.

HOW SHOULD I CHOOSE MY ICE CONTACT?

Ideally your ICE contact should know your basic medical information, such as blood type and allergies, and be able to help emergency services make decisions if needed.

WHEN COULD ICE INFORMATION HELP?

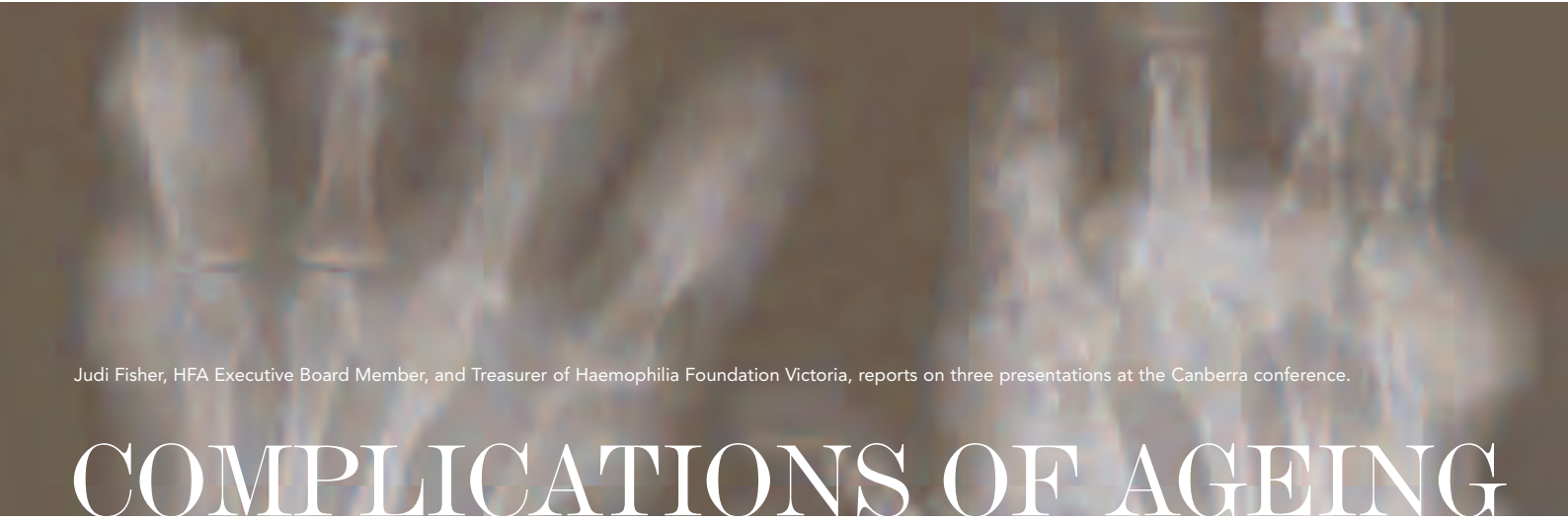
An ICE contact may be helpful not only in major accidents and emergencies, but any time you get into difficulty, for example, if you have had a bad tumble or a sudden asthma attack. It could also help reassure family members about the safety of those at higher risk such as the elderly and those with an illness.

WHO SUPPORTS THE AUSTRALIAN ICE CAMPAIGN?

Many Australian emergency organisations have thrown their support behind the ICE campaign and Telstra's education efforts.

WHAT IF A MOBILE PHONE IS LOCKED OR NEEDS A PASSWORD TO ACTIVATE IT?

Many mobile handsets are simply key-locked and can be accessed by pressing two keys. However, some mobile phones need a password to activate them, which is why Telstra recommends that people never rely solely on a mobile phone during emergencies.



Judi Fisher, HFA Executive Board Member, and Treasurer of Haemophilia Foundation Victoria, reports on three presentations at the Canberra conference.

COMPLICATIONS OF AGEING

Judi Fisher

Haemophilia and Cardio Vascular Disease – Associate Professor Alison Street

The most significant quality of life issue for the elderly haemophilia population is the burden of degenerative joint disease suffered by those who did not have prophylaxis and lived through periods of product shortages. But as they age they are also subject to the same issues experienced by the general population including vascular disease.

There is little published literature on this topic, but in a recent study, Sarah Darby and colleagues in the UK have reported a decrease in the death rate due to coronary artery disease in people with haemophilia, not infected with HIV, in comparison to the general population. It should be noted that this study was based on the information on death certificates, not on autopsy. However, compared with aged matched mortality data for the general population, it showed a 38% reduction for death due to coronary artery disease (CAD). Similar findings have also been reported in smaller studies from The Netherlands and Greece.

However, there is no reduction in the incidence of hypertension (high blood pressure) or high cholesterol levels in haemophilia and the incidence of kidney disease which predisposes to hypertension, is increased in haemophilia. In some cases this may be related to HIV, but the impact of repeated episodes of haematuria may be a significant factor.

People with haemophilia still get CAD which may require angiography and stent insertion or surgery. This requires careful planning with factor replacement and in some cases therapy to reduce the efficiency of platelets, another part of the body's clotting system. This can increase the risk of bleeding into joints and other sites in patients with haemophilia

The use of COX-2 inhibitors such as Celebrex may increase the risk of CAD and their use should be discussed with haemophilia centre clinicians.

There is no evidence of a similar decrease in the rate of cerebrovascular disease (stroke due to blockage of the arteries to the brain) or peripheral vascular disease (blockage in the arteries to the legs) in haemophilia.

The incidence of disorders of the prostate compares with the normal population but in haemophilia, the surgery is, naturally, more difficult and complicated and requires supervision by haemophilia experts. Osteoporosis, diabetes and cancer also occur as men age.

Advice to haemophilia patients:

- you are likely to live a long time;
- you are in charge of your own physical, mental and emotional health;
- you need to be sensible in maintaining a healthy weight, no more than moderate alcohol intake; and most importantly
- don't smoke.

Chronic Haemophilic Arthropathy – Professor John York

Prof York started by commenting that the management of haemophilic arthritis has come a long way since surgery was first conducted at Royal Prince Alfred Hospital in 1974 using cryoprecipitate.

The damage is caused by the impact on the synovium of repeated bleeds into a joint and the dense deposits of iron into the joint resulting in severe irritation. The main joints affected are the knee, elbow and ankle. Not having had the benefit of prophylaxis, this is a major issue for our adult haemophilia population

Acute bleeds usually result in sub-acute haemarthroses after two to three bleeds. Continued bleeds result in the progressive development of chronic haemarthroses.

We now manage bleeds with prophylaxis to maintain a factor level of around 10%. Physiotherapy also plays an important role, with our youngsters encouraged to develop strong muscles and to participate in activities such as cycling, swimming, walking and other non-body contact sports.

Acute bleeds can now be managed with adequate replacement therapy and the inevitable impact of joint disease is now mostly preventable.

For the older population, surgery is now a more viable option. The surgery must be carried out in a tertiary haematological centre where

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there are adequate supplies of clotting factor and where there are surgeons experienced in haemophilia.

There are problems associated with such surgery including:

- inhibitors;
- sepsis (especially with HIV);
- HIV, HCV, CJD, Others?

There is no satisfactory ankle joint prosthesis, but sub-talar fusion, yttrium and the use of orthotics can help. Elbow replacements are now a feasible option.

There is a high incidence of osteoporosis in adults with haemophilia, leading to an argument for screening this whole group. There is good treatment available using calcium, vitamin D and phosimax.

The old, but new problem of ageing – degenerative joint disease – will also impact as treatment increases longevity in the haemophilia population. We will need to manage degenerative joint disease in the hip, knee and spine. The management should be the same as for any other patients, including weight reduction, careful use of drugs and following strict principles for surgery.

Falls and balance – from research to practice – Marcia Fearns & Professor Keith Hill

Falls are a common problem in older people, but there has been little reported in research literature about balance dysfunction and falls for people with haemophilia.

A joint project between the National Ageing Research Centre and the Ronald Sawers Haemophilia Centre at the Alfred, evaluated the level of balance dysfunction in people with haemophilia (PWH) and the effectiveness of a home exercise balance program.

Initial testing was carried out on balance, mobility and confidence in a group of 20 patients with an average age of 39.4 years. Balance measures indicated moderate levels of balance problems for PWH.

There were compared to a group of 20 aged matched, healthy controls.

Following the initial assessment, a balance training program was prescribed for each individual. It was to be conducted at home for four months with follow-up assessments taking place during that period. In some cases, the program was modified to account for individual problems or needs.

Twelve patients completed the program and returned for a final re-assessment. Whilst the small sample size made it difficult to arrive at statistically significant results, there were improvements of 5-20% on most of the balance measures.

The results of this study are enough to suggest the value of static and dynamic balance performance in the routine physical assessment of PWH. Where reduced balance is present, physiotherapists should include balance training in addition to the usual approaches of using strengthening and flexibility exercises.

MARK YOUR DIARY!

Haemophilia Conference 2009, Brisbane
The Sebel, King George Square
8-11 October 2009
For further information contact HFA on
1800 807 173 or visit
www.haemophilia.org.au

Leonie Mudge is social worker for people with bleeding disorders at Royal Prince Alfred Hospital, New South Wales.

REMEMBER THE PHARMACEUTICAL BENEFITS SCHEME SAFETY NET IN 2008

Leonie Mudge

If you or your family need a lot of medicine in a calendar year, the Pharmaceutical Benefits Scheme (PBS) safety net may help you with the cost. All Australian residents, and people from countries with which Australia has a reciprocal health care agreement, are eligible for the PBS safety net. You can start your records from 1 January 2008.

People with bleeding disorders may obtain a lot of medicines through the hospital outpatient pharmacy. If these medicines are on the PBS list, they can be included on your PBS Safety Net Card. The safety net applies when you have spent the safety net threshold on prescription medicine. (In 2007, the threshold amount was $1,059.99 for general patients and $274.40 for concession cardholders.) These amounts are adjusted upwards annually and do not cover additional costs on more expensive brands of medicine.

What do I have to do?

Keep a record of your PBS medicine on a prescription record form which you can get from your pharmacy. Each time you have a PBS medicine supplied, hand your prescription record form to the pharmacist so the supply can be recorded. Your pharmacist might be able to keep a record for you on their computer, but if they can't or you visit different pharmacies, including hospital outpatient pharmacies, it is best to keep your own records. If you have a family, ask your pharmacist about combining the amounts you spend for your Safety Net total.

When you are close to reaching the Safety Net threshold, talk to your pharmacist about how you can apply for a Safety Net card. When your pharmacist has issued your Safety Net card, medicine will be cheaper or free for the rest of the calendar year. If you have a concession card it will be free, and if you do not have one you will be charged the concession rate only for PBS medicines.

For more information: www.medicareaustralia.gov.au – and the Australian Government Medicare Australia publication How to save money on medicine.

Kelly Brady is Haemophilia Social Worker at the Queensland Haemophilia Centre. She is also Co-Chair of the Australia/NZ Haemophilia Social Workers' and Counsellors' Group.

MAKING PEP HISTORY!

Kelly Brady

Preceding the 14th biennial Haemophilia Conference in Canberra, I was fortunate to be part of the group of social workers, counsellors, outreach workers, nurses and parents who attended Parents Empowering Parents (PEP) Train-the-Trainers program. The course was run over two and a half days, and while the course facilitators have taught it to over 680 social workers, nurses and parents from 100 Haemophilia Treatment Centres (HTC), it was the very first time they had taught PEP Train-the-Trainers course internationally (outside of USA where is was first developed). So this group was making PEP history!

PEP is a parenting course designed for parents of children who have a bleeding disorder. Parenting is complex, challenging and demanding, but also very rewarding. This program was designed and created for parents to increase their parenting confidence and skills. The course is 'taught' by a combined 'team' of social workers, nurses and parents. This is unique in that it provides opportunities for clinical and experiential contribution from professionals and parents respectively.

The content is designed to increase the parent's understanding of haemophilia; encourage a therapeutic relationship between parent, child and HTC staff; and provide practical information and skills that parents can use to build on their existing parenting skills that can be referred to time and time again. The program is delivered in a supportive environment that enables parents to meet other parents, share experiences, and exchange ideas and advice relating to raising a child who has haemophilia. It's important to remember that not every parent has the same experiences as another parent, or holds the same parenting style, therefore, respecting different point of views is essential in maintaining a supportive and non-judgemental environment.

The course is typically delivered over four days, however the facilitators have had experience with running it weekly over 10 weeks, or during a 'getaway' weekend. I think most of us agreed the latter was the most appealing for parents and professionals alike! At the completion of PEP Train-the-Trainer course, staff and parents go on to teach the course to other parents. Hundreds of parents have attended PEP at the local HTC. One of the advantages of PEP is that the course can be tailored or moulded to meet the needs of parents attending the course.

The PEP course was held in a hotel in Canberra, a few days preceding the Conference. This hotel is where we all slept, ate, and attended the course. The hotel was the source of a few Faulty Towers experiences which provided us with some entertainment, laughs and room changes. Fortunately the Faulty Towers experiences were resolved early on and we were looked after well with good food and a much needed complimentary drink at the hotel bar at the end of each day.

So, our PEP course kicked off on Monday afternoon, starting with introductions and icebreaker activities where you're usually asked to reveal something about yourself to a room full of mostly strangers! Well the PEP course didn't disappoint, as that's exactly what the facilitators got us to do! In fact, they even phrased it as revealing a 'secret' about ourselves, which was met with a few groans and gasps! However, the group embraced these activities, and ended up being a wonderful source of humour, fun, laughter, and personality, with no startling 'secrets' revealed, which was a relief!

After introductions and 'secrets,' the three facilitators, Ed Keubler (social worker), Danna Merritt (social worker, and creator and co-author of PEP), and Madeline Cantini (nurse), explained the outline of the course content. PEP comprises of ten sessions facilitated by haemophilia social workers, a haemophilia nurse and parents. PEP encompasses classroom discussions (and yes, some of us did feel like we were back at uni or school!), role plays (we definitely felt like we were back at school!), and hands-on exercises to educate parents about effective parenting.

We each received a very heavy (I hope no-one had to pay excess baggage on the way home!), yet comprehensive PEP manual, which contains the course content and an appendix on everything you need to run a PEP program. The content is split into two sections – 1) for the facilitators of the course and 2) for parents attending the course. We all found it a bit tricky co-ordinating the two sections of the manual at first, with sheets of paper flying everywhere, people looking at the wrong pages, and a few frustrated and bewildered looks, but I think we all found a way of getting around this after the first afternoon.

It was on the first day that the facilitators revealed to us that WE, the course attendees were going to TEACH the sessions over the next two days!!! It was at this point, the blank stares and gasps began to fill the room. I thought the facilitators must be very jetlagged to announce a statement such as this. I think most

PEP encompasses classroom discussions (and yes, some of us did feel like we were back at uni or school!), role plays (we definitely felt like we were back at school!), and hands-on exercises to educate parents about effective parenting.

of us, if not all (from the looks on people's faces) were hoping they were jetlagged and a correction would soon be made. I overheard someone say, "This is not what we signed up for" and "THEY'RE the facilitators, why aren't they teaching it to US?" But the words we had heard were true, it wasn't a joke. We were split into five groups and allocated two sessions per group to "Teach Back" to the wider group which consisted of colleagues and parents who we either knew very well, somewhat well, or not at all. Little did we know, we were about to get to know each other very well! We realised we weren't going to be sitting back for two days, making a few notes and eating the lollies that were placed on our desks - we were going to have to do some work!

Most of us were concerned as we didn't know the content and were going into this cold. Talk about being out of our comfort zones. The preparation time was well utilised during and after each day's training. Some groups purchased bottles of wine from the hotel bar and found a quiet space to prepare their 'Teach Back' while others decided to attack it the next day after spending the night dreaming about their 'Teach Back' – myself included! I think the only reassuring aspect was that we were all in the same boat, and from the comments openly and honestly shared before, during and after the 'Teach Backs' that became even more apparent. I think this eased us all, well maybe just a little bit!

The 'Teach Back' provided much humour; hairy questions from pretend parents, ie our 'supportive,' in-the-same-boat colleagues; fast talking Australians who the American facilitators couldn't understand!; and lots of chanting of "Who's the Parent? You're the Parent!" and this is only a small image of the antics and fun that occurred. There were plenty of laughs, bursting personality and a variety of 'parenting' going on! Amidst the jokes and laughs, the group learnt from colleagues and parents' 'Teach Back' sessions, and ideas were formed to implement in their own teaching groups in the future. The inclusion of parents on the teaching team adds a unique dimension. I don't think the group would have experienced what we did without their input and contribution. So a big thank you to the parents.

At the end of the 'Teach Backs' we breathed a sigh of relief, looked forward to our complimentary drink at the hotel bar again, plus a few more of the non-complimentary type, and discussed and made notes in our PEP Work Plan booklets on how we could roll out the program in our State, Territory or in New Zealand, HTC.

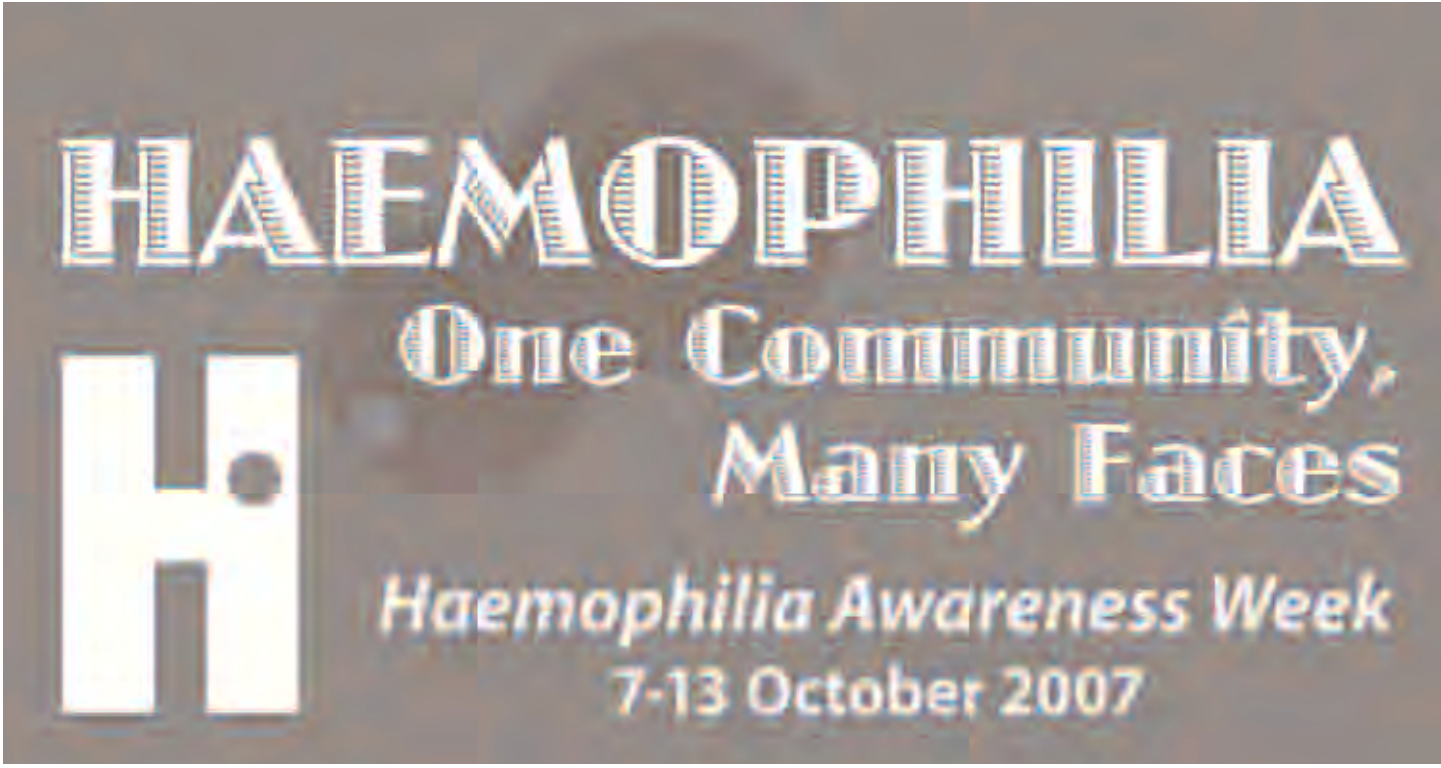
To conclude the training in true group work style, the facilitators informed us we were going to finish off with the ball of yarn activity. Most social workers are well acquainted with this activity. This is how it works, everybody forms a circle, standing shoulder to shoulder, you need a large ball of yarn/wool, and one person ties the end to their finger and then chooses a person in the circle to throw it to and then says why they have chosen that person, hopefully complimentary words!! Then that chosen person does the same to another person (remembering to tie the end piece of yarn to your finger) and it's repeated until everybody is chosen. The 'tapestry' of yarn is then placed on the floor which represents the 'weaves' of the preceding days.

At the conclusion of the training we wished one another well and thanked each other for the experience and learning, as well as the laughs and fun. Clare Reeves, HFACT Counsellor, represented the group by expressing a vote of thanks to the wonderfully experienced (but jetlagged!) course facilitators who provided inspiration and encouragement. We now look forward to implementing the PEP course in Australia and New Zealand in the future.

Note from the Editor:

The PEP training was proposed by representatives of the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group after the Vancouver Congress in 2006. HFA and HFNZ worked together to make the training available before the Canberra conference. The training was part funded by Bayer NZ, HFA and HFNZ.

HFA is keen to facilitate a roll out of this training for health professionals and families in States/Territories around Australia during 2008. Talk to your Haemophilia Foundation or haemophilia nurse or social worker at your Haemophilia Centre if you would like to participate in the training.

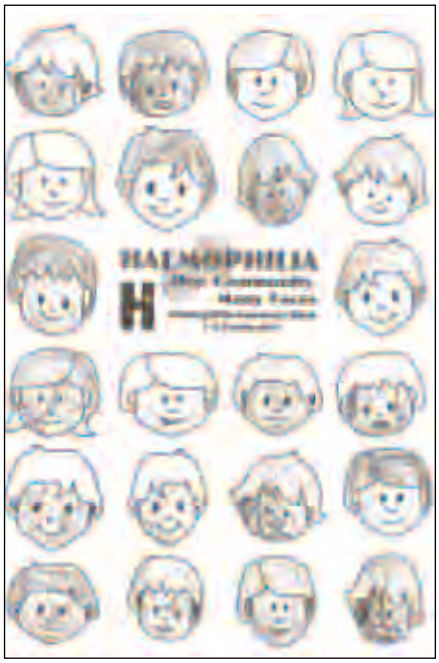


The theme for the week - **Haemophilia ~ One Community, Many Faces**, aimed to portray that haemophilia affects people of all ages and experiences.

HFA and Haemophilia Foundations around the country worked together to raise awareness about inherited bleeding disorders to the general community, community organisations, governments and service providers.

The week was successful with 20 print media stories, including articles in the Woman's Day and That's Life magazines and there were 5 radio interviews. Great feedback and interest was expressed by people in the community who did not know very much about haemophilia or other bleeding disorders, nor that a support network for people with bleeding disorders is available.

Many people participated in Haemophilia Awareness Week and shared their personal stories in the media and the community.

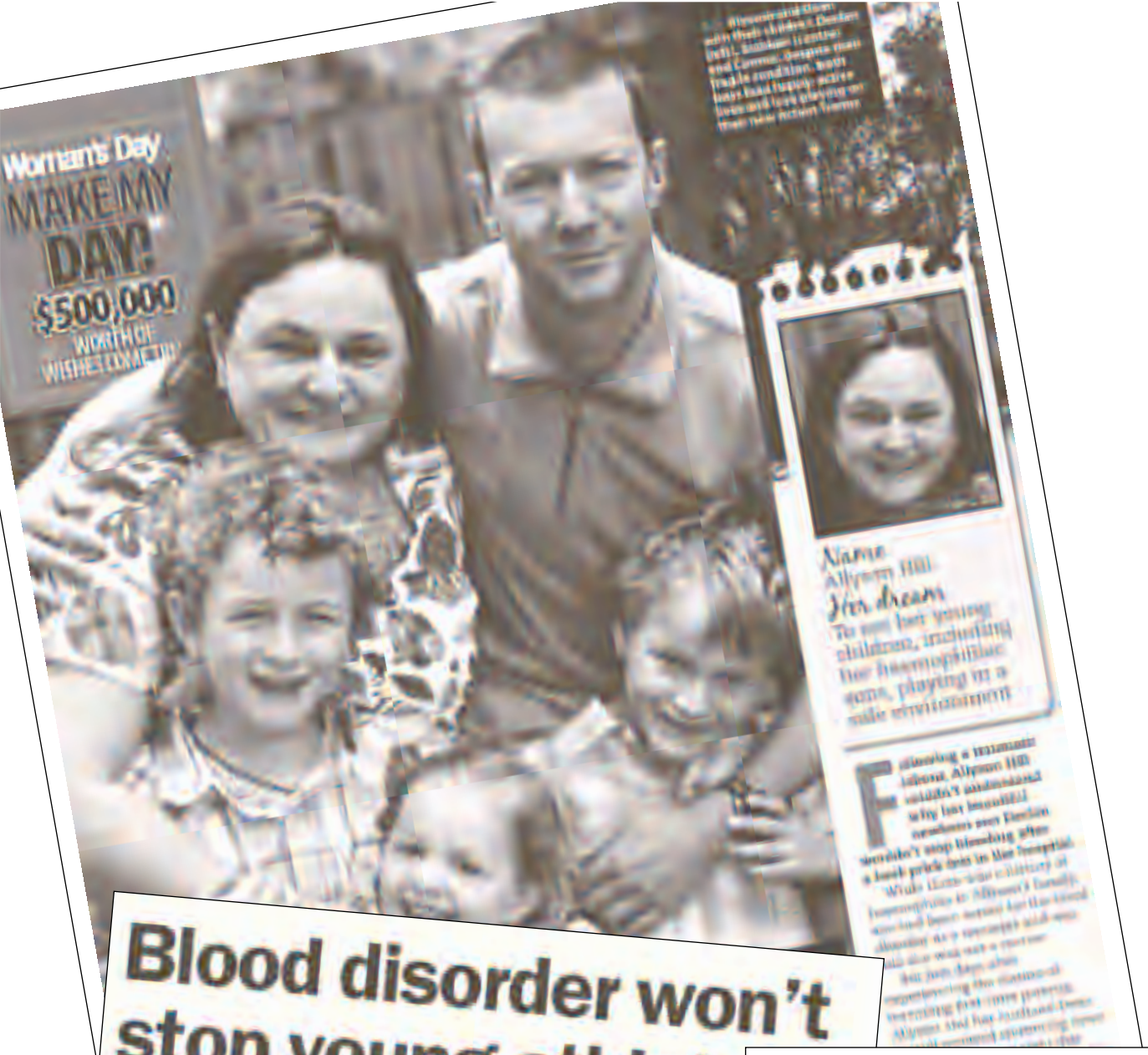


The results of the Haemophilia Awareness Week Colouring Competition were:

5 years and under - **Taylah from Hillside, Vic**

6-9 years - **Richie from Bellbowrie, Qld**

10 years and over - **Shaylee from Malanda, Qld**



Blood disorder won't stop young athlete

By Marcus Power

HAEMOPHILIA will never hold back Jarrod King.

The 19-year-old University of Ballarat student was diagnosed with the blood clotting disorder at eight months of age.

But what makes his story unusual is that Jarrod has no known family history of haemophilia and his twin brother Nolan does not have the disorder.

Mr King said that while coming to terms with his condition was hard as a child, by his middle high school years he made the choice to accept it was just a part of life.

"It's just a part of my life now. I've learnt to deal with it," Mr King said.

With the the risk of serious injury ruling out contact sport, Mr King turned his attention to swimming and football umpiring, and has excelled at both.

He made the trials for the Australia Commonwealth Games swimming team and he umpired VFL football for the first time this year.

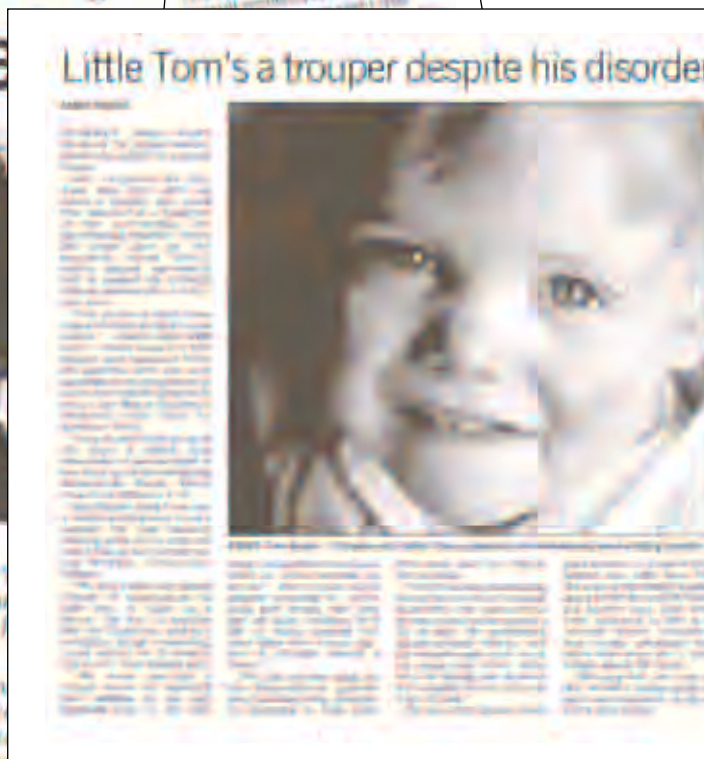
A haematology clinic named him the

Jarrod King

chance to officiate at last week's Cup under-18 grand final, to go on to be on the AFL umpiring panel in 2010.

During Haemophilia Awareness Week this week, Mr King wants to raise awareness of the disorder so kids does not have to define their lives

He said advances in treatments of the disorder had given sufferers more options.



Mother's instincts tested

HE may look like any other mischievous four-year-old but young Sam Campbell takes life's knocks harder than most. Northside Chronicle journalist **James Chalmers** finds out more about haemophilia.

■ Visit the Haemophilia Foundation Australia website at www.haemophilia.org.au.

It's in the blood, so take

THE VISION AND LEADERSHIP AWARDS

The second round of Vision and Leadership Awards has been announced by Haemophilia Foundation Australia (HFA) and applications will be received until the closing date of 31 March 2008.

The Vision and Leadership Awards were established in 2007 through an initiative of HFA and Wyeth to give men and women affected by haemophilia and related bleeding disorders opportunities to achieve new goals. The Awards are administered and controlled by HFA with funds provided by Wyeth.

The Awards will give people an opportunity to undertake an education activity or project to enhance their personal development or career or attend a conference, or program to develop skills for leadership and participation in the bleeding disorders community.

Applicants are encouraged to consider what would make a difference to their life and seek assistance through this award opportunity to achieve success or reach a new goal or objective.

Up to five individual awards of $2,000 each will be made to successful applicants in either of the following categories:

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

Application Form

The application form can be downloaded from the HFA web site at www.haemophilia.org.au or request a form from HFA on 1800 807 173 (freecall).

Closing Date

Applications must be received by HFA by 31 March 2008. No late applications will be considered.

VISION AND LEADERSHIP SUCCESSES

Michael Cerantola

Michael lives in Victoria and is a recipient of the inaugural Vision and Leadership Awards.

I was thrilled to receive funding through the Vision and Leadership Awards so I could undertake the training and testing for my heavy combination and dangerous goods licences. I passed half of the course and I was allowed to use the funds which were set aside for uniforms (boots, shirts, pants and a jacket) to re-train and re-sit part of the driver education course which I had not completed. I am now the very proud owner of both licences, and this has resulted in me getting full-time casual employment carting recycled water. I have a job lined up carting LPG in the future, but at the moment this job carting water will give me good experience. As you could imagine, LPG is quite different to water for safety!

Another bonus has been that I have not had a day off work due to bleeds, as the job is working so well for me. The opportunity has provided me with the employment I was seeking. How good is that?

Dale Spencer

Dale is a Youth Leader and member of Haemophilia Foundation Western Australia. He travelled to Canberra for the Conference due to his Vision and Leadership Award. The following is an extract of his report.

The 2007 Australian & New Zealand Haemophilia Conference in Canberra was a great opportunity for me to expand my own knowledge of what's happening in Australia and around the world with topics such as hepatitis C, HIV, treatment and haemophilia in general. I am a newly appointed Youth delegate for Western Australia and Canberra was my first opportunity to meet and mingle with doctors, physiotherapists and others, but most importantly, my fellow Youth Committee members, and parents with newly diagnosed children.

The sessions were relevant to everyday life.

For me, it was great to see the doctors, physios and anyone who has treated me as a people who I could talk to. I am at the age now where I can relate to information I'm given and share my story with other people. My role for HFWA now will be to help the younger generation of people with haemophilia to manage their disorder and have fun in life, and also so the parents can see and realise that their child doesn't have to be treated differently.

CALENDAR

XXVIII International Congress of the World Federation of Hemophilia

Istanbul, Turkey, 1-5 June 2008
www.wfh.org

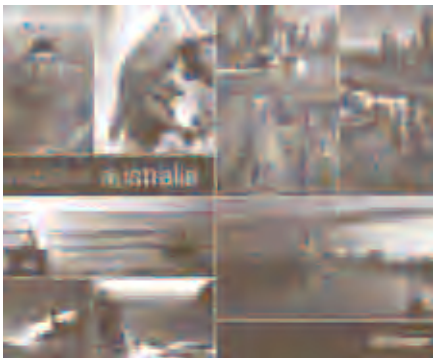
20th Annual ASHM Conference
Perth 17-20 September 2008
ph 02 8204 0770
fax 02 9212 4670
email conferenceinfo@ashm.org.au
www.ashm.org.au/conference

6th Australasian Viral Hepatitis Conference

Brisbane 20-22 October 2008
ph 02 8204 0770
fax 02 9212 4670
email
conferenceinfo@hepatitis.org.au
web www.hepatitis.org.au

Haemophilia Conference 2009

Brisbane 8-11 October 2009
ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au
web www.haemophilia.org.au



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

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

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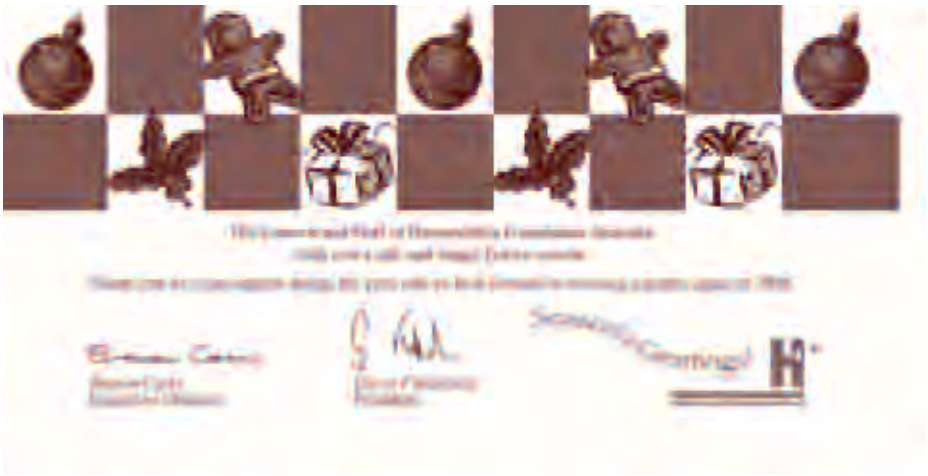

Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health and Ageing which makes this publication possible.