National Haemophilia
Haemophilia Foundation Australia
www.haemophilia.org.au
No. 177, March 2012

WORLD HEMOPHILIA DAY / APRIL 17

WHAT WILL IT TAKE TO CLOSE THE GAP?

World Hemophilia Day 2012
April 17

An estimated 1 in 1,000 women and men has a bleeding disorder. However, 75% still receive very inadequate treatment or no treatment at all.

Together, we can work towards a day when treatment will be available for all around the world.

Help us Close the Gap
www.wfh.org/whd/en

WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

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HAEMOPHILIA FOUNDATION SOUTH AUSTRALIA (HFSA) UPDATE

Sharon Caris

As previously reported in *National Haemophilia*, HFSA took steps in 2010 and 2011 to gauge the interest of members to continue to operate as an incorporated association with the objective of representing people with bleeding disorders in South Australia (SA).

The small group of volunteers was challenged by a lack of numbers at meetings and gradually it became clear to those who were still involved that there was insufficient interest locally for the group to continue. In 2011 HFSA was advised that it would be prudent to wind the organisation up. This saddened the volunteers, but they understood it was necessary to pass a motion to wind the organisation up. Several of the volunteers plan to keep in touch with one another for social activities.

The HFA Executive Board discussed the situation and how the interests of the community in SA could still be represented. It was agreed that Paul Bonner, President at the time HFSA was wound up, would be invited to participate at the HFA Council as an observer. Paul has accepted this invitation and will also continue in his role at HFA as a mentor to youth.

HFA will advise health department officials in SA of the above developments and check that arrangements are in place to ensure consumer participation in policy development in SA which might impact on people with bleeding disorders and their families and carers.

HFA has strong relationships with health professionals at the Haemophilia Centres in SA and will continue to consult with them as we do with others around Australia. Each of the Haemophilia Centres has indicated health professionals will make *National Haemophilia* available to people who attend each of the Centres.

Before HFSA wound up, a decision had been made to transfer HFSA funds to HFA for safekeeping until HFSA is in a position to formally operate again. These funds will be held by HFA in a special purpose account. HFSA also recommended that the interest from these funds be used for the benefit of people with bleeding disorders in SA and their families. Although criteria has not yet been established for how this might work, it may be possible to use the funds to assist with project work in SA or to support people to attend conferences, camps and workshops, for example.

HFA is keen to maintain contact with people with bleeding disorders in SA and their families, so please feel free to make contact with Sharon Caris or other HFA staff to raise any issues or concerns you think we may be able to help with.

Gavin Finkelstein is President, Haemophilia Foundation Australia (HFA)

FROM THE PRESIDENT

Gavin Finkelstein

I think most people who will need to swap to a different recombinant factor VIII product because of the changed National Blood Authority supply contracts will be aware of their options by now. If you haven't spoken with your haemophilia specialist doctor, you should do so in plenty of time as you will need to have transitioned to a different product before 1 July 2012. Changing product is never an easy decision, but unfortunately you may have no alternative but to change to one of the other two products available because yours may not be available in Australia after 1 July. Your doctor will be able to talk with you about any risks and advantages of the different products.

The HFA position remains as it has always been since the establishment of the new supply arrangements in 2003. There should always be a choice of products for people with bleeding disorders and people should make their treatment decisions in consultation with their treating health professionals. We believe best practice is for a choice between different products and multiple products where products are similar. Whilst it is disappointing that some people will need to change to another product, it is crucial that we have access to an adequate supply of safe and effective products, and we are satisfied this will be the case with the new supply contracts. We expect in the future there will be many more products available as companies bring more products to market and this will create further challenges.

HFA is currently making arrangements for its representatives who will be attending the upcoming World Hemophilia Congress in Paris. The Paris Congress is our key opportunity for Australia to promote the 2014 Congress, and we will work hard on this while we are there.

Although it is not possible for HFA to provide full funding for many people to attend the 2012 Congress, we have put aside a small amount for community members who have made a decision to go to the Congress "under their own steam". At this stage we do not know how many people might seek our assistance; however we hope to be able to cover the cost of registration of community members who apply. Please contact Sharon Caris at the HFA office for details of how to apply.

After the Paris Congress, we expect to establish working parties and committees to work towards the 2014 Congress. Although it seems like a long time away, and it feels like only yesterday that we were bidding for the Congress in Argentina, the time will fly and we have a lot of work to do. We want the 2014 Congress experience to be the best ever! As well as encouraging people from around the world to come to Australia, we also need to encourage large numbers of delegates from Australia, New Zealand and the region to attend. Congress is a very important event which generates revenue for World Federation of Hemophilia's development activities and we need to play our part in making it a success.

The Paris Congress is our key opportunity for Australia to promote the 2014 Congress

Sharon Caris is Haemophilia Foundation Australia Executive Director.
Suzanne O'Callaghan is Haemophilia Foundation Australia Policy Research and Education Manager

HFA REPRESENTATION AND ADVOCACY ROUNDUP 2011

Sharon Caris and Suzanne O'Callaghan

HFA takes an active role in monitoring the ongoing national work to review and restructure the health and social services systems and ensuring that bleeding disorder interests are represented, and 2011 was another busy year for us.

Over the last year HFA has made several submissions to government and other regulatory or professional bodies on policy matters including:

- Government tenders for haemophilia treatments
- Blood donor deferral and treatment product safety
- Disability care and support
- The government processes to approve and subsidise medicines
- New hepatitis C antiviral treatments
- National hepatitis C testing policies
- Managing blood borne viruses in health professionals.

Representation of bleeding disorder community interests can also take place at a national committee level. HFA staff and volunteers were invited or nominated for several special expert committees to represent consumer views and expertise including:

- The Australian Red Cross Blood Service Advisory Committee on the Safety of Blood Tissues and Organs
- The NH&MRC Transmissible Spongiform Encephalopathies Advisory Committee
- The National Blood Authority Technical Evaluation Committee
- The Australian Bleeding Disorders Registry Steering Committee
- The Medicines Australia Code of Conduct Committee.

HEPATITIS C ADVOCACY – WHAT IS HFA DOING?

Financial issues for people with bleeding disorders affected by hepatitis C continue to be a high priority for HFA. With the deterioration of some community members' health and financial circumstances, the need for a solution is becoming increasingly urgent. HFA has had further correspondence and meetings with governments about this issue, and about the HFA proposal for a financial assistance scheme.

HFA asked affected community members for more information in early 2011 and this highlighted that the out-of-pocket costs not covered by existing government schemes and financial safety nets are a serious problem. This information was documented and discussed in correspondence with the federal government during 2011.

The HFA advocacy will continue with representations to the new Health Minister Tanya Plibersek and her support staff.

HFA would like to thank the community members who contributed their personal experiences to this consultation.

Some of their personal stories on the complications of living with a bleeding disorder and hepatitis C follow:

"I tried out combination therapy for hepatitis C but it didn't work. I live in a regional town but my partner and I both had to give up work and come and live in the capital city for months while I went through the treatment. The side effects were severe and I needed my partner to care for me. Normally my partner needs to keep working to pay the bills. There was a big loss of income for us and we completed the paperwork for a carer allowance but it kept being returned with a note saying that we did not meet the criteria. It has been very stressful for me and my partner."

"My liver disease is getting worse and I have had treatment a couple of times but it wasn't successful. I try to deal with the depression and the fatigue but I worry that I'm not able to adequately perform my duties at work. With haemophilia and hep C

WORLD HAEMOPHILIA DAY APRIL 17 2012

- **An estimated 1 in 1,000 women and men has a bleeding disorder. However, 75% still receive very inadequate treatment or no treatment at all. What will it take to close the gap?**
- **On World Haemophilia Day 2012 help us "Close the Gap" of care around the world. Together, we can work towards a day when treatment will be available for all globally.**
- **On World Haemophilia Day we want to inspire people to help close the gap and to improve accessibility and quality of care so that Treatment for All becomes a reality.**

I have used up my sick leave in the first couple of months of the year and there is no money left for extras. You apply yourself, struggle and deal with issues as they arise or persist, but when you do go looking for help or assistance there seem to be too many hurdles in your way and it just gets too hard and you wonder what the point is. With a little extra assistance it would make a difference to my life. I would be more inclined to use alternate therapies, or other treatments as the financial burden would not fall solely on myself."

Every year on April 17, World Haemophilia Day is celebrated around the world in order to increase awareness of haemophilia and other inherited bleeding disorders.

World Haemophilia Day was started in 1989 and the World Federation of Hemophilia (WFH) chose April 17 in honor of WFH founder Frank Schnabel, who was born on that day. On April 17, help us spread the message to "Close the Gap" of care around the world.

Together, we can work towards a day when treatment will be available for all globally. Join the international bleeding disorders community on April 17 to mark World Haemophilia Day. Raise money to help WFH close the gap for international projects by "**Wearing Red on World Haemophilia Day**", and donate online at https://www.haemophilia.org.au/donation or send your donation to HFA 1624 High St, Glen Iris VIC 3146. All donations will be redirected to the World Federation of Hemophilia.

Sharon Caris is Executive Director, Haemophilia Foundation Australia

OUR GLOBAL BLEEDING DISORDERS COMMUNITY

Sharon Caris

HFA is currently preparing for the World Congress in Paris and the General Assembly of the World Federation of Hemophilia (WFH). These important events will be held in July this year and will be hosted by WFH with the support of the French Hemophilia Association, the local National Member Organisation (NMO).

The Congress will also be supported by hundreds of volunteers from around the world who will be presenting on their areas of expertise or chairing education sessions during the congress program or workshops. All participants come together with a shared passion to make a difference. This shared passion spreads across our worldwide bleeding disorders community and includes people living with bleeding disorders and health professionals involved in their treatment in both the developed and developing world. They all want to see the gap bridged between those who have access to adequate treatment and care and those who as yet still do not have sufficient treatment or none at all so that everyone with bleeding disorders worldwide can reach their full potential and live without life-threatening bleeds and pain.

WORLD HAEMOPHILIA DAY

In this publication we encourage all our readers and supporters to celebrate World Haemophilia Day on 17 April, when WFH and NMOs will highlight the ongoing needs of the world wide community as well

Thai twinning

as celebrating the successes. It is an amazing achievement that WFH will be celebrating its 50th anniversary in 2013. We have also reprinted WFH President Mark Skinner's article "Advancing on all fronts", published in the December publication of *Hemophilia World*, which describes treatment advances and future challenges.

WORLD FEDERATION OF HEMOPHILIA (WFH)

At the upcoming General Assembly, Haemophilia Foundation Australia (HFA) and the other 118 NMO's members will vote for President, Vice-President Medical, Vice-President Finance, two medical members and two lay members. Of interest to our part of the world is that Australians have been well represented on the WFH Executive Board for the last 4 years by Rob Christie in his role of VP Finance and A/Prof Alison Street, as VP Medical. The WFH Executive Board faces a huge change this year as their terms expire and new Executive members are elected. The HFA Executive is currently considering nominations and will actively participate in discussions with other haemophilia community volunteers around the world about the way forward. The new WFH Executive will lead many new initiatives, as well as existing programs and plans so the WFH family of volunteers will continue to build on achievements so far.

The WFH successes are also attributable to the programs put into effect by the WFH staff. The WFH "machine" has grown over the years and it now has a staff of 44 people based in the Montreal offices. We look forward to meeting John Bournas in Paris. John was appointed to the role of Executive Director of WFH after Claudia Black left the organisation last year after many years of incredible service. John and his team in effect bring together the vision of the Executive by coordinating a mammoth effort of identifying experts, coordinating volunteers, with their own expertise and training to put programs into action. These programs will continue to drive the future successes of WFH as it works to improve care and treatment around the world.

CLOSING THE GAP OF TREATMENT AND CARE

Some of the most important WFH programs are those that build the capacity of NMOs to reach out and strengthen their local community and also to support others where they can. HFA and the bleeding disorders community in Australia has very much benefited from the international successes and we have made much progress here in terms of access to adequate supplies of clotting factor, and treatment and care. We still have some gaps that we want to improve on, and our advocacy is focused on these things, but the gaps in Australia are at a different level from those in the developing world.

The ease of travel to congresses, the internet and social media technology have brought HMOs closer together, on one hand, but they have also made the differences in access to treatment more immediate. HFA receives many requests through facebook and email for support and assistance from people around the world who need treatment but do not have access to it locally. It is very sad that we have to reply that we cannot send clotting factor to those who need it. But we can encourage them and share our own experiences of development, and point them to WFH programs that might help them now and into the future.

TWINNING

One of the great WFH successes has been its twinning programs between haemophilia centres and NMOs. These twinning programs are a way of building and strengthening capacity in emerging haemophilia centres by working with an established haemophilia centre to seek government recognition and commitment to greater resources for treatment provision. Several Australian haemophilia centres have been involved in such twinning relationships over the years. Some are currently involved in providing training experiences for doctors, laboratory staff, physiotherapists, socials works and nurses in their haemophilia centres. These programs involve an incredible commitment from health professionals who work in a voluntary capacity to share their expertise in their own time.

As a patient organisation we can also play a small part in improving the capacity of NMOs to advocate for our members, and to develop skills and expertise needed to adequately represent the local community. Although HFA is coming to the end of the "official" part of its twinning

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Being at a congress presents some very sad and frustrating situations and challenges, but it is always inspiring to see and hear about what is being achieved to improve the lives of people living with bleeding disorders and their families

Thai twinning

partnership with the National Hemophilia Foundation of Thailand and the Thai Patient's Club under the WFH Hemophilia Organisation Twinning program, our relationship will continue with our Thai friends. We will encourage and support our Thai partners as they continue their regional outreach work, and develop administration processes and policies to assist them to run their organisation more effectively.

WFH helped us to establish this partnership and all the HFA representatives who have been involved and our members who have met Thai representatives at HFA conferences over the last 4 years know the friendship between the organisations has given us far more than we have given. HFA has learned a great deal from its twinning experience with Thailand. It has been a two-way street of sharing ideas and learning from each other. The energy, drive and innovative approach of emerging NMOs can inspire experienced NMOs to revisit the way they work with their communities. In this issue of *National Haemophilia* you will read an article from Colleen McKay about the beginning of twinning partnership which is being established between Cambodia and the Haemophilia Foundation of New Zealand.

WORLD CONGRESS PARIS 2012

The upcoming congress in Paris is a great opportunity for people who can attend to learn more and experience the strong friendship of the worldwide bleeding disorders community. Everyone feels that, and experiences it, no matter what their role is. I have no doubt that people living with bleeding disorders (and their families and carers if they attend) find congresses both uplifting and confronting at the same time, as do health professionals, government policy makers, and industry representatives in attendance. Being at a congress presents some very sad and frustrating situations and challenges, but it is always inspiring to see and hear about what is being achieved to improve the lives of people living with bleeding disorders and their families. The experience motivates everyone in attendance to play a part in improving things locally in their own domain and it also affirms their commitment to the WFH vision for Treatment for All.

Congresses also provide WFH with an important revenue stream to supplement other fundraising efforts to support the increasing number and range of programs. HFA will be at the Congress in Paris to actively promote the 2014 Congress because we want to encourage as many people as we can to come to Melbourne to make the 2014 Congress a great success for Australia, and more importantly for WFH!

In December HFA President Gavin Finklestein signed a contract with WFH President Mark Skinner, in Melbourne as the first formal step in our working relationship towards the 2014 Congress. We have every reason to make the Congress a community and financial success. So, when you start to hear more about the 2014 Congress, please consider how you might participate and play your part in this important work.

This article was published in *Hemophilia World*, vol. 18, no. 3, December 2011, the magazine of the World Federation of Hemophilia and is reprinted with permission

ADVANCING ON ALL FRONTS

Mark W. Skinner

EVOLVING THERAPIES TO ACHIEVE TREATMENT FOR ALL

Over the past 50 years, we have seen enormous advances in therapies to treat bleeding disorders. Although access and availability vary widely around the world, our understanding of coagulation, prevention, and treatment is far different than in 1963, the year the World Federation of Hemophilia (WFH) was founded.

In the early 1960s, fresh frozen plasma (FFP) was the principal therapy available for the treatment of hemophilia. At the time, the US National Hemophilia Foundation (NHF) commented in its brochures: "The hemophiliac cannot live unless his blood is induced to clot by the addition of normal blood (or blood plasma) ... and now there is fresh frozen blood plasma which can be stored to provide a constant life-saving supply." Poignantly, the brochure also included a call to "sponsor needed research which will some day bring a cure or a control, by solving the mystery of blood coagulation." These words certainly ring as true today as they did in the early 1960s. Although many mysteries have been solved, many still remain.

By the mid-1960s, Dr Judith Graham Pool was responsible for the next major advance. She published a method of preparing concentrated factor VIII from thawing FFP, giving rise to what we know today as cryoprecipitate. In announcing Dr Pool's discovery, the NHF Medical Bulletin stated: "Over the past several years there has been increasing recognition that concentrates of anti-hemophilic globulin have a distinct role in the treatment of hemophilia ...The expense involved in the production has hampered the development of such concentrate...It is difficult to predict... the exact role that the concentrate developed by Dr. Pool...will finally play in the treatment of hemophilia."

The expense of research and the resulting treatment advances, whether it be the discovery of cryoprecipitate or the quest for a cure, has challenged our community since the very beginning. Therapies once thought to be expensive to produce are now relatively affordable when compared with present-day therapies. We should not presume therapies coming to market today will be unaffordable in the future, even where they cannot be purchased presently. Over time, they will have an equally significant global impact.

Since the 1960s, we have experienced an amazing revolution in the way bleeding disorders are treated. The availability of plasma-derived factor concentrates, and more recently their recombinant analogues, has brought an improved quality of life for many around the world. However, this did not come without a cost. The toll of HIV and hepatitis transmitted by cryoprecipitate and the early generations of factor concentrates, manufactured in the 1980s and early 1990s, is still being felt today.

Although current generations of treatment products have a robust safety profile, over 40 per cent of the countries reporting treatment product usage data to the WFH indicate FFP and cryoprecipitate are still used for treatment of hemophilia.

It is important that we not only think about how to improve the current state-of-the-art products, but also ways in which existing therapies, important to an equally large percentage of the world's population, can advance as well. According to data from the Market Research Bureau, over 75 per cent of clotting factor concentrates are consumed by those living in regions representing just over 15 per cent of the world's population.

Arguably, we are on the cusp of another revolution in treatment, potentially as big as that brought on by the discovery of cryoprecipitate in the early 1960s. Over the next few years, we will see treatment product advances on all fronts. These will range from virally inactivated (solvent detergent) cryoprecipitate; biosimilars (generic biologics) of current therapies, which will expand availability and improve price competition; treatment products with substantially enhanced efficacy that will last two or three times longer in preventing bleeding; to the increasingly real prospect that through gene transfer a "cure" may become a reality.

It is worth remembering our vision of Treatment for All includes far more than simply access to treatment products; management by a team of healthcare specialists trained in bleeding disorders is fundamentally important. The full value of these advances will remain unknown or intangible without a proper care framework.

There will be no single pathway to improving access and affordability around the world. It is entirely feasible that each of these advances will have implications for the development

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of care, whether a country is resource poor or rich. If you think of the telecommunications industry, there are countries in the world today that have skipped over landlines from limited or no telecommunications infrastructure to cellphone technology. Decisions on the most appropriate therapy will remain a local decision based on local circumstances and individual preferences.

It is difficult to predict what each of these therapies will mean for the future of our global community, but there is no doubt that we are in a golden age of research and development, which has the prospect of revolutionizing Treatment for All once again.

According to data from the Market Research Bureau, over 75 per cent of clotting factor concentrates are consumed by those living in regions representing just over 15 per cent of the world's population

Colleen McKay is Manager – Outreach Services, Haemophilia Foundation of New Zealand

LIVING WITH HAEMOPHILIA IN CAMBODIA

Colleen McKay

THE ISSUES AND STRUGGLES - SO DIFFERENT

THE BENEFITS OF A STRONG PATIENT ORGANIZATION - THE SAME

It was with much excitement and nervousness and little idea of what to expect that in 2010 Richard Scott from Auckland, parent of Andrew with severe haemophilia, and myself headed off to Phnom Penh in Cambodia along with Robert Leung from the World Federation of Hemophilia (WFH) for an Assessment Visit to establish the viability of twinning between the two countries. At the end of this visit, Haemophilia Foundation of New Zealand (HFNZ) and the Cambodian Hemophilia Association (CHA) applied to WFH to enter into a formal twinning arrangement. The overall goal of the Twinning Partnership is to build a strong and effective Cambodian Hemophilia Association.

The twinning application was accepted and after a year of email contact Catriona Gordon, mother of two boys with haemophilia, and I headed to Cambodia for our first official twinning visit in November 2011. During this five day visit we met with CHA Committee members, held family meetings, visited hospitals in Phnom Penh and Siem Reap, and met with representatives from the Ministry of Health. Our main contacts with CHA are Mr Sithan - Chairperson of CHA, Mrs Linat - Secretary of CHA, Dr Chean Sophal - Haematologist in Phnom Penh and Dr Sing Heng - Haematologist in Siem Reap.

During our visit it was amazing to see the impact donated factor from WFH has had on patients in Cambodia. When I first visited Phnom Penh in 2010 Sithan, the Chairperson of CHA, was unable to walk without the aid of a crutch. One year later, it was incredible to find that he now walks unaided as the availability of some donated factor VIII to treat bleeds has enabled Sithan to build up his leg muscles.

During our first meeting with the CHA committee, Dr Sophal was called out to see a haemophilia patient in the ward. There we met 3 year old Justin, who has a severe factor IX deficiency, along with his mother and other family members. Dr Sophal explained that unfortunately WFH had not been able to donate factor IX products recently, and that he currently had none available to give to this boy. The family must purchase their factor from Thailand at a cost of $US250 per 500IU bottle. Justin is a normal, extremely busy and inquisitive young boy and uses a bottle of factor IX every 2-3 weeks. After his last bleed he required twice weekly prophylaxis for 4 weeks, creating quite a financial burden for the family. This is the harsh reality of living in Cambodia – access to factor replacement is extremely limited, at times non-existent, and places huge financial pressure on families.

Phnom Penh Pediatric Hospital is a series of three-story concrete buildings. In one building, the outpatient clinic is located on the ground floor with Dr Sophal's office

and the ward on the first floor. The building seemed very large and the proportions of the halls and rooms very generous. We soon realised that this was due to a lack of clutter, such as the machines, supplies, and trolley beds that normally fill hospitals in developed countries.

The other notable absence in the ward was that of patients. On the day that we were there, just one patient was in a ward of at least eight beds. The empty beds were simply plastic mattresses on wire woven beds. In addition to paying for their treatment and hospital stay, patient's families must supply everything for the patient, including bedding and food. The treatment room where the children receive their factor was in the corridor next to a nurses' station with no comforts and no privacy.

Due to shortages in the blood supply, when someone requires blood in Cambodia their family are required to arrange donations equivalent to the amount of blood that the patient has received. This policy creates many difficulties for families with disorders such as haemophilia and thalassemia where multiple donations are often required. It is commonplace for families to pay strangers to donate the blood for them. Where factor replacement is not available, whole blood transfusions may be the only option for people with haemophilia and the blood transfusion policy may prevent them getting even this most basic of treatments. While meeting with representatives from the Ministry of Health we learned of Cambodian Government plans to manufacture their own plasma-derived treatment product – cryoprecipitate. We also learned of their plans for the further development of 'Blood Drives' to encourage all Cambodians to donate blood for the use of the general population.

We also travelled with CHA representatives to Siem Reap in the north of Cambodia. There we met with eleven boys and young men with haemophilia and their families, some of whom had travelled great distances from the Provinces over poorly maintained roads for the morning meeting. Mr Sithan introduced himself and presented the mission of CHA. In her presentation, Catriona introduced herself and her boys with haemophilia and outlined the benefits of her involvement with HFNZ. My presentation described various HFNZ activities and events which enable families to get together for mutual support.

Listening to the questions that followed our presentations quickly highlighted the importance of effective information and education about haemophilia, and the support that can be provided by a patient organisation. The question 'when will my child be cured of his haemophilia?' was asked many times. One mother was saving for a trip to Japan as she had heard there was a cure available there. In developing countries such as Cambodia the concept of 'living' with a chronic condition such as haemophilia is quite foreign. Their reality is that when you contract an illness either you are cured or you die. To try to help translate the concept, Catriona further spoke to talk of her two sons and how that although they are healthy and have good lives, they still hurt themselves, they still need their factor infusions, and that they will always have haemophilia.

We returned to Phnom Penh for a meeting with local families with haemophilia at the hospital. This was the first time that most people at the meeting had heard about CHA and by the end of the morning all twelve families in attendance became members. During discussion groups the participants were asked to suggest possible CHA activities for the future. Interestingly the activities are much the same as might be suggested no matter where you live in the world. These included:

- Mother's Discussion Group
- Young Adults Lunch
- Youth Camp
- Family Events - Visit to Dreamland, Evening Boat Cruise
- Annual Educational Workshop

Even though in Cambodia the struggles and issues with haemophilia are difficult, there is so much benefit that can achieved just by removing the isolation that comes with this rare disorder and providing opportunities to get together, to learn, to discuss, to support each other and to have fun – just the same we do here in New Zealand and in Australia.

The Twinning Program itself is for a period of 4 years, from 2011 until 2014. This week long visit was to start working through the aims that had been set earlier, and together with CHA officers to set some clear and achievable goals for the coming year. Since our humble beginnings in 1958, HFNZ has grown into a solid, well-organised and prominent patient organisation. We look forward to working together, sharing our experience and supporting CHA in the years ahead as they begin their journey.

Meeting a family at Phnom Penh Hospital

Meeting with families in Siem Reap

Hospital ward

Kate Walton is Haemophilia Foundation Australia Youth Project Officer

HFA YOUTH PROJECT UPDATE

Kate Walton

The HFA Beyond Prophylaxis youth project started in April 2011 and I joined HFA to lead the project in August 2011. The project is funded by a government grant and a donation from a charitable foundation. As there is little information about the impact of bleeding disorders on young people in Australia, the project will assist in better understanding the needs of young people and will create some communication and education resources to respond to their needs. The project is part of the broader planning for the future of HFA and the bleeding disorders community in Australia and for future programs to meet the needs of members.

The aim of the Beyond Prophylaxis project is to enable young people to make positive and informed choices about their lifestyle. The project involves developing an accessible and attractive web site as a communication platform that young people will be able to access and connect, share experiences and obtain information about relevant life and life style choices, including work, travel, sport, recreation, relationships and socialising.

YOUTH WORKING GROUP

A key part of the project has been to form a national Youth Working Group (YWG) of young people affected by bleeding disorders, who are playing an active part in deciding what the communication tool will look like and what information it will provide. The YWG were recruited through State/Territory Foundations, health professionals and advertising in HFA publications.

It is important to make sure young people's experiences and preferences drive the development of the project. To start the consultation with the YWG, I have emailed YWG participants two to three questions per week about the current issues they may be facing, how they prefer information presented to them and how they consider the best way to promote the website. Most responses have now been received, and the answers have been collated and YWG members have been sent a summary of the results. This information is very valuable as we are now gaining a solid understanding about the impact of bleeding disorders on young Australians. I would like to thank the YWG for taking the time to answer all of the questions and for their honesty.

The numbers of the YWG are growing as young people continue to make contact. I am keen to have a substantial representation of young people in the YWG, so have encouraged young people to join and answer the consultation questions as they hear about the project rather than stopping the recruitment on a particular date. Currently there are 25 young people in the YWG. So far every state is represented except for Northern Territory and new members are always welcome.

NEEDS ASSESSMENT REPORT

The needs assessment has involved consultation with the YWG, state and territory Foundations, the HFA Youth Committee, haemophilia health professionals and parents about issues for young people. The findings of my consultation since August 2011 will be published in the needs assessment report. A preliminary report was completed in January 2012, and a final report will now be prepared as all of the results have been received and the consultation in the weekend workshop has taken place. There is already evidence for follow on work to be undertaken at the end of the current phase of the project, and HFA is exploring this. I appreciate the efforts of everyone who has answered the consultation questions so far as they have provided direction to the project.

YWG WEEKEND WORKSHOP

The weekend workshop was held on 24 – 26 February 2012 in Melbourne and was run at a training facility with computer and internet access. The YWG were asked to submit expressions of interest to attend the weekend workshop and a group of young people were selected to attend. Over the weekend the YWG played an active role in shaping the content and structure of the website. The results of the consultation process provided a focus for the topics discussed during the weekend workshop. Topics that were brainstormed included the future of the YWG and how to continue involvement and engagement with the wider group of young people affected by bleeding disorders. We

If you are aged between 13 and 30 and are interested in working with Kate on the Beyond Prophylaxis project, contact her on kwalton@haemophilia.org.au or phone 1800 807 173.

Kate would also like to talk to parents of young people with bleeding disorders about the issues they may be facing at the moment.

YOUTH NEWS

also considered how to involve young people who are currently not engaged in this project and how to talk about sensitive topics. The YWG did a great job in answering all questions, staying attentive and focused. Their dedication, hard work and their efforts over the weekend are greatly appreciated.

YOUTH WEB SITE

The project involves the development of a youth web site to work as a communication tool for young people with bleeding disorders. Following a tender process during December 2011 and January 2012 a web design company has been selected to develop the website. The company has experience both in innovative web site development and working with youth projects. They have done some preliminary work on the project with me and ran a session with the YWG at the weekend workshop to develop the design further.

The development of the web site tool by the design team and follow up testing will occur from March to May 2012. This is an opportunity for more people in the community to get involved and become a part of the Youth Project, as community members will be invited to assist in evaluating the site.

THE YOUTH WORKING GROUP WEEKEND WORKSHOP

The HFA Youth Working Group (YWG) met in Melbourne for a weekend workshop in February 2012. Their job was to contribute ideas on how to make tools to communicate with other young people with bleeding disorders, suggest tools that will work and give feedback on what the web site should include and look like.

YWG members and Kate at the weekend workshop

THESE ARE THEIR IMPRESSIONS OF THE WEEKEND

Dale, WA

A group of 8 other fellow young people from all around Australia and I came together to brainstorm and develop a program and web site, with the intention of helping youth all over the country to get in touch.

We worked on the questions of how, why and what and came to the conclusion that there should be a youth based website, mainly for the ages of 13 to 30, with subjects such as peer support and travel advice. There will be a frequently asked questions section, and comments will also be able to be posted after each article.

We discussed issues such as the sort of tool we will be developing,

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how we will go about developing it, copyrighting laws and managing age groups. Two gentlemen from the web site developing company called twenty4 also came in to discuss topics to be added to the web site with us.

Stephen, NSW

For me, the highlight of the weekend was obviously being able to work together to build a resource that will be very informative and helpful. I'm looking forward to seeing the site take off, and many people using it to its full potential. And I have learned never to trust dolphins, or hobos!

Sam, NSW

The workshop itself was incredible, and was held in a massive building although we were only on level 2. The hotel we stayed at was good, and the dinner and breakfast was tasty and plentiful! During the Saturday session we were asked to brainstorm the major topics and the way that the information was going to be presented on the web site and then looked at other web sites to see their ideas. Although not much was decided upon on the Saturday session, after the web designers visited and the refinement during the Sunday session, we had the web site panned out, and it was pretty awesome.

Geoffrey, ACT

Over the course of the weekend we discussed our ideas for the new youth haemophilia website, which is hopefully being launched in the near future. We are still in the early stages of the project, but so far it looks like it will shape up to be a very useful tool for young people with haemophilia. Two of the guys from 'twenty4' came in and helped us put our thoughts onto paper; this was great as it showed us a very rough draft of how the web site might feel.

The web site is looking to be largely a place for young people with haemophilia to meet others involved in the community and hear their stories, learn how to cope with haemophilia in sport, travel and other common hurdles people with haemophilia face, and lastly a way of keeping up to date with current events such as camps and conferences.

Despite a very strange "short" film that has left me with an uncommon dislike for dolphins, overall the weekend was another really good experience and I am enjoying taking a more active role in the haemophilia community. If all goes to plan, I look forward to meeting many more young people in a similar situation to my own and reading what they have to say.

Richard, TAS

The main focus of the workshop was to design and give ideas on a web site for young people with bleeding disorders in Australia that will be separate to the current HFA web site. The purpose of this was to involve more people from the ages of 13 to 30 in communicating with each other. The workshop covered many things and there was quite a bit of debate on how we could make the web site while still sorting out things like privacy, plagiarism and information. We were all asked many questions and had lots of help from the guys from twenty4 (web designers). It wasn't all just work but also a lot of fun. It was a great experience and I encourage all young people out there wanting to do more about their problems to explore the web site and help us make it better.

Lauren, QLD

This weekend provided an opportunity for us to come up with an exciting plan for how we can start to really engage the youth of our community. The highlight of this weekend for me was the ability to really nut out what we all hope to achieve from the youth web site, with some fun along the way. I have learnt about some of the very extensive work that goes in to creating a web site. The weekend provided the perfect platform for planning exactly what we want this web site to be, and how to use it to engage other young people in our community who may not be currently as involved as they want to be. My hope is that this web site will be used as a tool for young people to communicate with each other, for the sharing of experiences, and access to easy-to-understand and succinct information, as well as the ability to ask questions in a safe and understanding environment. I would highly encourage any young people who want to know more to get involved with their state and national Foundations, and help us out to make this web site a real success.

Jenna, TAS

The workshop gave us the opportunity to shape our new youth web site. We spent two days discussing all the ins and outs of the new web site, from content and

structure to the look, as well as some complex issues such as moderation of comments, privacy concerns and how to address embarrassing and personal questions. It wasn't all work though, with the serious stuff separated by games, a scavenger hunt and an evening out at the Shadow Electric cinema (even though the movie was not quite as expected…). The weekend was a fantastic chance to catch up with friends and meet new people, and we made some great progress on the content and look of our new web site. It will be exciting to see how it looks once our professional consultants have finished putting together all our ideas, and I hope we can be a great help to the rest of the youth bleeding disorder community in the coming years.

Andrew, VIC

Young people from across Australia gathered together, all with the same purpose. Living in a world of social media, technology and personal hand held devices, one of the best ways in communicating to a large audience of youth and getting them together especially in the haemophilia community is via the internet.

The young people discussed how this could best be done, developed, moderated and the general layout of what they thought was important to have. The challenges faced with creating something for a broad community and a community that sometimes doesn't stay in touch at the best of times was the highlight of discussions. Creating something fun, entertaining, and a website that would keep the community coming back was the main goal.

Meeting with website developers and nutting out the problems or road blocks that could be faced was an important part of the weekend - along with many discussion and Q&A sessions on what the young people thought would the best direction to go in.

Overall the weekend was informative, productive and everyone left with the same objective in mind, to create a website for youth, by youth.

WHAT'S HAPPENED TO MY YOUTH NEWS?

Youth News is going to be a section in National Haemophilia while the youth project is in development. Stay tuned for further information.

Suzanne O'Callaghan is Haemophilia Foundation Australia Policy Research and Education Manager

FACILITATOR'S REPORT

Suzanne O'Callaghan

Melbourne turned on its best summer weather for the Youth Working Group (YWG) weekend workshop on 24 to 26 February 2012. Eight young people and one mentor from around Australia flew in to Melbourne to take part in a think tank on developing an innovative web-based communication tool for young people affected by bleeding disorders. Kate Walton, the HFA Youth Project Officer, and I facilitated the workshop and aimed to work with the group to pull together the ideas for a clear concept by the end of the weekend.

It was a challenging task – to create a solution that would work in an area where many have tried and often failed. My role was to give some ideas on how this might fit with HFA's other strategic work and some technical knowledge about web sites and social media technology, like facebook.

The YWG put both the left and right sides of their brains to work in an assortment of different activities:

- Brainstorming on what should be covered in the web site and what sections it should include
- Mockups of web pages
- Creating artwork for the web site
- Thinking through how to manage tricky issues like talking about sensitive issues and moderation
- Coming up with strategies to reach other young people with bleeding disorders and take the project into the future.

On Saturday afternoon, Zaac and Matt from Twenty4, the design group developing the web site, held a session to refine the group's ideas for the web site and looked at what young people consider to make a web site attractive. It was a really interesting way of seeing what was important and helped clarify the group's priorities.

The result of the think tank was amazing: a wall of ideas for the web site, some very creative ways of involving young people in a web space that focuses on what is really important to them, and an exciting pathway into the future. And some fantastic photos as artwork to kickstart the web site!

If the workshop put the YWG through their paces, the weekend's social activities were a test of Kate's resourcefulness. As a special treat Kate had booked the group into a picnic at the Zoo's Twilights Concert on Saturday night. At 5pm on Friday night we were dismayed to find that Vanessa Amorosi, the lead act, had been admitted to hospital and the event had been cancelled. It would have been a great shame to waste the lovely Melbourne evening, so after some hurried consultation of open-air programs, the group was rebooked into a picnic at the Abbotsford Convent followed by a film at the Convent's Shadow Electric open-air cinema. After a very odd trailer about a homicidal hobo, we settled to watch *The Big Blue*, a

Kate leading the workshop

French classic film about a young man who is a world champion free diver and seems to be turning into a dolphin – but our adventures were not yet over, and after two versions of the film broke down, we found ourselves watching the director's cut (nearly 3 hours long, in French with English subtitles) instead of the original snappy two hour English version. It was a memorable film and dolphins found their way into a lot of our conversations!

The YWG were a great team to work with and came up with some very innovative ideas. We're looking forward to the next step, which is to develop a beta version of the web site for community testing. See Kate's article in this issue of *National Haemophilia* for more information.

Anne Jackson is Clinical Practice Consultant – Haemophilia at Women's & Children's Hospital, Adelaide

PARENTS EMPOWERING PARENTS IN SOUTH AUSTRALIA

Anne Jackson

In August 2011 eleven parents of children with haemophilia in South Australia undertook the Parents Empowering Parents (PEP) program. The program, widely established in the US, is designed to educate parents and offers skills to effectively parent, leading to confident, successful, happy children.The program is presented to parents by parents of children with bleeding disorders, in tandem with a social worker and nurse. This team approach combines the strengths of peer support with professional expertise. The PEP program is designed for parents for children from 0-11 years old and the goals of the program are to:

- Increase parents' understanding of the child's bleeding disorder
- Provide the parent with skills necessary to effectively parent the child at the earliest age possible
- Heighten the parent's ability to respond objectively and consistently to bleeding episodes
- Enhance the therapeutic relationship between parent, child and treatment staff

The program focuses on parenting techniques and challenges relating to having a child with a bleeding disorder.

Thanks to the contribution and commitment of the parent facilitators Caroline Sheppard and Raelene Kennewell the program was well received by the parents that attended. The program was supported by Haemophilia Foundation Australia and funded through generous financial support from Pfizer, Novo Nordisk and Haemophilia Foundation South Australia. The Adelaide program was the second time the program had been run in Australia with the first program held in Perth in 2009.

Feedback from the parents was positive and all the parents responded that they would recommend the program to other parents. These are some comments from parents who attended:

"I found the course to be very useful and helpful. Gave me a chance to reflect about myself and my parenting techniques. It was a comfort to know there are others in the 'same boat'."

"This weekend has been a real eye opener and highlighted how much we need to learn, or should I say 'we don't' know'! Listening to the other parents really enforced our belief in 'they're boys first, haemophilia is second' and treat them as such"

To have Sharon Hawkins (haemophilia social worker, WA) and Peter van der Linden (social worker, SA) providing and facilitating the program alongside parents Raelene and Caroline was a great opportunity to provide support to the parents who took part in the program. The participation by parents in particular demonstrated the commitment that the parents had to improving their knowledge on bleeding disorders and caring for their children.

Many thanks to the parents who attended and the facilitating team.

For more information, visit the PEP Program page on the Hemophilia Foundation of Michigan web site: http://www.hfmich.org/?module=Page&sID=pep-parents-empowering-parents

Caroline Sheppard

Raeleen Kennewell

PEP Adelaide 2011

Abi Polus is Clinical Physiotherapist in Haemophilia at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

BENEFITS OF EXERCISE, SPORT AND TRAINING FOR PEOPLE WITH HAEMOPHILIA

Abi Polus

There has been a big shift in thinking in the role of exercise in people with haemophilia. Historically, most exercise was discouraged as it was thought that this may increase bleeding, however research has proven this incorrect. It has been found that both targeted exercises for specific muscles and joints and general fitness and exercise can help prevent bleeding and is beneficial to keeping joints, muscles and the whole body healthy.

It has been found that people with haemophilia may have specific muscle weakness around certain joints, and a lack of balance, proprioception (feedback from the joints to the brain that help prevent injury) and small, stabilising muscles (especially around the ankle, shoulder, knee and the 'core' Transversus Abdominis muscle in the deep stomach/support for the spine). If these muscles are not working correctly it can lead to other injuries. Having good muscle strength and length may also prevent potential injuries which could lead to a bleed.

Exercise regimes and programmes that address these issues, in addition to general fitness programmes that will not aggravate painful and degenerated joints, are immensely beneficial. Additionally, exercise helps with weight management which can decrease the pressure on painful joints and can even give relief from pain.

A good general gym program has a warm up at the start and a warm down at the end that includes stretches and gentle muscle work, and a mixture of aerobic exercise and safe and graduated weights and stability exercises. If you are unable to weight-bear (due to post-operative instructions, pain in hips/knees/ankles on exercising, or for another reason) the pool can be a great place to exercise with specific joint and muscle exercises, walking in the water, and cardiovascular aerobic work such as swimming and deep water running.

For specific exercises or to discuss what sport or class or gym program best suits you, or for an individual gym program that can be tailored for your own specific needs and goals, contact the physio at your Haemophilia Treatment Centre.

A GENERAL HAEMOPHILIA EXERCISE/GYM PROGRAM MAY INCLUDE:

General fitness and weight management (aerobic exercise)

Balance and proprioception (brain that can help prevent injury) and stability

Pilates/ core work

Proper technique

Specific joint strengthening; slowly and progressively:

- Lower traps
- Quads, hams, calves

Correct and effective stretching

Bone density

Non-pounding exercises

Pain free exercises

Exercises in water.

WHAT TYPE OF EXERCISE SHOULD PEOPLE WITH HAEMOPHILIA NOT DO?

The type of exercises prescribed and the effect that they will have on your body should be discussed with your gym/personal trainer if you have one or your physiotherapist. In some weight lifting exercises that build up muscle, the aim is to break down and tear fibres in order to get hypertrophy (big bulk). This may cause a bleed, especially if done too fast or with weights that are too heavy or with incorrect technique.

Additionally overstretching a muscle may cause stress and potential bleeding to a muscle. If a joint is contracted or fixed it should NOT be stretched beyond its usual limit or into pain. This will cause a bleed and potentially further damage into the joint.

Contact sport is usually discouraged due to the increased potential for injury, although this is not always an absolute. Contact the local Haemophilia Treatment Centre physiotherapist for advice on contact sports.

Boxing training can be of great cardiovascular benefit but actual sparring for training could cause harm if you receive a blow to the body. Any sport where the aim is to land a blow on a participant's body should NOT be done by people with haemophilia.

Trish Godden was formerly the Haemophilia Foundation Australia Direct Marketing Manager
Suzanne O'Callaghan is the Haemophilia Foundation Australia Policy Research and Education Manager

ACHIEVING A DREAM

Trish Godden and Suzanne O'Callaghan

Chris Gordon is a young community member with severe haemophilia and was interviewed by Trish Godden

What if you are passionate about playing Australian Rules Football, but have severe haemophilia? How can you keep doing something you love and avoid the high impact injuries that young men often experience with football?

Chris Gordon is a remarkable young man who has been able to balance his dreams and the reality of having severe haemophilia. Now 22 years old, Chris is an Australian Football League (AFL) umpire and studying primary school teaching.

At 6 years of age Chris's mother took him to watch his first AFL game. Her team, Melbourne, was playing at the Melbourne Cricket Ground on a Friday night. It was an inspiration - the game, the lights, the size of the stadium and all the people. Chris knew then that AFL would be his passion.

At 7 years of age, Chris started playing AFL Auskick locally with his mates, and continued for the duration of his time at primary school. Auskick is an AFL program to introduce children to Australian Football and through it Chris learned general co-ordination and skills and played football games regularly.

However, when he left primary school, Chris struck the problem that many young boys with haemophilia experience – he was entering a stage of life when the size and weight of the players would increase dramatically and the impact of a contact sport would be much greater, and his haematologist advised him and his parents that Chris should stop playing AFL as it would be too dangerous.

Chris tried very hard to prove to his haematologist and his parents that it would not be a problem for him, but they were not convinced. He might have lost involvement in the game he loved so much, but a friend's father suggested he try boundary umpiring. It was a new pathway for Chris and enabled him to stay part of the game, even though he was not playing football, and he trained, was on the grounds and in the rooms afterwards with his mates.

Chris threw his drive and energy into improving his skills and performance: running, fitness and accuracy were crucial to his new role. With skill, training and commitment he progressed from local, to Victorian Football League and finally AFL umpiring. The highlight for him was his selection to boundary umpire the 2011 AFL Grand Final – a great achievement for a young AFL umpire.

For Chris, having severe haemophilia has never been a reason not to participate. He has had prophylaxis treatment to prevent bleeds since he was two years old and has self-infused his treatment since he was an adolescent. With the independence this gives to him, he has been able to go on school camps and travel. His contact with the Haemophilia Centre is regular but not intrusive, with an annual appointment, contact to organise documentation for travel, and face-to-face visits only if needed, and Chris considers haemophilia has had minimal impact on his lifestyle. He feels his high level of fitness has given him greater resilience, strong muscles to support his joints and better health.

What is next in the pipeline for Chris? He is currently training to be a primary school teacher, with a view to becoming a Physical Education teacher and managing school sporting events. It will be a great way for the wider community to benefit from Chris's positive attitude and ability to find a way to achieve a dream.

"Haemophilia is not a barrier to most things in life," says Chris. "The main thing is to give most things a go."

A highlight – Chris umpiring the 2011 AFL Grand Final

Suzanne O'Callaghan is Haemophilia Foundation Australia Policy Research and Education Manager

CARRYING THE HAEMOPHILIA GENE – A PERSONAL STORY

"Jo" (not her real name) carries the haemophilia gene. She was interviewed by Suzanne O'Callaghan

Jo always had an idea there was "bleeding" in her family, but haemophilia was never mentioned. So for many years she thought her heavy bleeding problems with her menstrual periods and haemorrhaging after her daughter's birth were just unfortunate problems that any woman can experience. Now in her 60s, she reflects back on her experiences of bleeding and what she has learned about women and haemophilia.

"In those days your parents weren't exactly up front about haemophilia. Mum used to just say that some of the older family members were 'bleeders' and that's all she said," commented Jo. "It wasn't until my sister had her son and found he had haemophilia that we became aware there was haemophilia in the family. By then I had already grown up with all the bleeding problems and given birth to my daughter and haemorrhaged and never known what caused it."

Jo knew she had a bleeding tendency, but didn't make much of it.

"You just put up with it, I guess. It was awful – very embarrassing! I used to have huge clots with my period, which are quite difficult to manage. You don't get a lot of warning when the blood can suddenly run down your leg. It was awkward and I was always trying to work things around having my period. I would never go out in a white dress and I always had to be near toilets when I went out so that I could change every hour."

Heavy periods took their toll on Jo's health, but the lack of specialist knowledge about how to manage her bleeding disorder made it difficult to treat her bleeding symptoms effectively.

"When I was about 17 or 18 the doctor who was trying to help me with my periods thought I had pernicious anaemia. He prescribed vitamin B injections for 3 months, but they didn't have much effect.

Every menstrual period was an ordeal. "I didn't like to take time off work, so I was lucky that the worst days usually occurred on the weekend. My periods used to last for 7 or 8 days – it felt like you didn't have much of a break from having your period.

"In my late thirties, my periods became shorter but I would bleed as much as I had in 7 days in two or three. I always felt giddy or dizzy and nearly passed out whenever I had my period. It couldn't go on and I had a hysterectomy when I was 40 years old."

About 25 years ago, a few years after Jo's nephew was diagnosed with haemophilia, Jo, her daughter, her sister and some nieces were tested to see whether they carried the haemophilia gene. Testing at that stage was only for factor VIII levels.

"Back then the testing was a bit uncertain," said Jo. "You would have a blood test that gave an 80 or 90% probability that you carried the gene, but even then it was not necessarily accurate. They thought I was probably a carrier but couldn't be sure. I found out for sure with the genetic test in 2006. It's amazing how testing has changed, thanks to DNA!" Jo's genetic test in 2006 identified the genetic mutation causing haemophilia in her family.

The genetic testing technology to give Jo a clear answer about her carrier status may have been developed, but medical knowledge about women with bleeding disorders among health professionals in the community is still catching up. Even recently, although her carrier status was known to her cardiologist, Jo was prescribed a combination of a non-steroidal anti-inflammatory drug and aspirin to help her heal after a heart operation and needed intervention from the Haemophilia Centre to manage the bleeding complications she experienced.

Bleeding disorders are rare in the community and it is not surprising that many of the health professionals Jo has encountered have not been familiar with the specialist care required. However, Jo has found that their attitudes can make a big difference to complications with medical procedures.

Some years ago Jo had a number of teeth extracted and bled quite badly. "My sister had tried to tell the dentist that there was haemophilia in the family and I could be a carrier," said Jo, "but the dentist said that it doesn't matter, haemophilia only affects boys."

In contrast, she has found that the doctors who are prepared to speak with the Haemophilia Centre and find out more are more likely to learn about the complications and short-circuit any potential problems. "My GP is a brilliant doctor but he didn't know a lot about my bleeding disorder to start with," Jo commented, "but I know that he has checked up a lot in between my appointments without him even saying so because every time

I see him, he has so much more information."

Jo's experiences have taught her the importance of taking more control of her care. "It's easy to think it's not important, or that you haven't had problems before so you won't now," she said. "Or to be too embarrassed to ask questions or change doctors. But if something goes wrong, you are not in any position to argue. You need to be prepared."

Jo's suggestions:
Learn about your bleeding disorder and be well-informed yourself. Be vigilant about the medications you are prescribed and don't be afraid to ask questions about everything.

Contact your Haemophilia Centre first before you have a medical procedure and discuss the procedure with them and what you need to know. Ask your doctor to speak with your Haemophilia Centre before undertaking the procedure – and check that they have.

Shop around until you find a doctor who works well with you and with the Haemophilia Centre. Listen to the answers they give to your questions – if they are a bit dismissive or are fixed on knowledge they learned at university and are not prepared to talk to the Haemophilia Centre and find out more about you and your bleeding disorder, or they do not want to treat someone with a complicated health problem, it might be time to find another doctor. Your Haemophilia Centre may also be able to tell you which specialists they have worked with before.

"It's worth taking the time to find the right doctor for you. When you have chronic health conditions, you need doctors who can provide your care over your lifetime. And when you have a problem, knowing what to do and having the right people around you can really make a difference to your life."

CARRYING THE HAEMOPHILIA GENE - ISSUES FOR GIRLS AND WOMEN

Many girls or women who carry the gene causing haemophilia do not have symptoms of a bleeding disorder. However, some may have a bleeding tendency. Females who have bleeding related to haemophilia are often described as "symptomatic carriers". If their factor levels fall in the range for mild haemophilia (5 – 40% of normal clotting factor), they may sometimes also be referred to as having "mild haemophilia".

Examples of having a bleeding tendency or symptoms may include:

- Bruising easily
- Having heavy menstrual bleeding
- Having excessive bleeding after dental surgery or extractions, other surgery or accidents
- Have prolonged bleeding after childbirth.

All females who carry the haemophilia gene should have testing for their clotting factor levels periodically, as their factor levels may change with age, pregnancy and hormonal medications. If their factor level is low, they will need a treatment plan to manage situations if they occur or prevent them.

MANAGING SYMPTOMS

Heavy bleeding with menstrual periods (*menorrhagia*) may be a symptom of a bleeding disorder and can involve:

- Heavy menstrual periods (e.g., soaking through a tampon and pad around two hourly, or needing to change during the night)
- Menstrual bleeding for longer than normal (e.g., longer than 8 days)
- Bleeding with clots bigger than a 50 cent piece in size.

Heavy menstrual bleeding can lead to anaemia (low red blood cell count/low blood iron levels), with symptoms of fatigue, paleness, lack of energy and shortness of breath.

Although these can be symptoms related to haemophilia, they can also be symptoms of a gynaecological disorder, so it is important to consult a gynaecologist.

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Paul Brou

With diagnosis and appropriate treatment, these bleeding problems can usually be reduced or managed.

If you are a woman or girl with a bleeding disorder, a holistic or comprehensive care approach to your health care can help you to achieve better health and quality of life. Specialist gynaecological care over your lifetime is important to manage any gynaecological issues that occur. These may not be related to haemophilia, but in some cases the bleeding disorder may make the bleeding problems worse.

At times in their life, some symptomatic women may need to have gynaecological surgery or procedures. If this happens, it is important that this is managed in a team, with discussion between the woman, the Haemophilia Centre and the gynaecologist and/or surgeon.

Ideally your medical care team should work together on your health care and should include:

- A gynaecologist
- A haematologist specialising in bleeding disorders
- A GP or paediatrician or obstetrician, if relevant at the time.

GENETIC TESTING

A normal factor VIII or factor IX factor level test does not mean that a girl or woman does not carry the haemophilia gene.

There is a genetic test for haemophilia and finding out whether a girl or woman carries the haemophilia gene is a process which may take some time. This can involve:

- Meeting with a genetic counsellor
- Looking at the family tree to identify other family members who may carry the haemophilia gene
- Blood tests for other affected family members, if known, to identify the particular gene alteration causing haemophilia in her family
- Laboratory tests on a blood sample from the girl or woman to see if she has the same family gene alteration
- A blood test to check clotting factor levels if they are not known.

Genetic counseling is available to girls or women and their parents or partners and many find it helpful. The Haemophilia Centre can help with information and advice about genetic testing and provide a referral to a genetic counsellor.

PREGNANCY AND CHILDBIRTH

With good management, women who carry the haemophilia gene have no more problems with delivering a healthy baby than other mothers.

How to prepare:

- Ideally, if you are planning a pregnancy, contact your Haemophilia Centre for a referral to a genetic counsellor
- When you become pregnant, contact your Haemophilia Centre for advice on local obstetric services they already work with
- Ask your haemophilia and obstetrics teams to consult with each other to plan for a smooth and safe pregnancy and delivery and care for the newborn
- Check with your Haemophilia Centre before having any invasive procedures, such as amniocentesis
- Discuss suitable choices for anaesthesia, especially an epidural, with your Haemophilia Centre and obstetrics teams.
- A normal vaginal delivery is usually recommended unless there are obstetric complications.

TIPS FOR WOMEN WHO CARRY THE HAEMOPHILIA GENE

You are not alone

- Stay in regular contact with your local Haemophilia Centre team and make sure you keep up with anything new. The Haemophilia Centre is there to help and can give you advice or talk over any problems or concerns
- Keep in touch with your Haemophilia Foundation for updates on new information and enjoy a chat with other women who know what it's like

IF YOU HAVE A BLEEDING TENDENCY

- Let your dentist or your doctor know you have a bleeding disorder and advise your Haemophilia Centre team in advance of planned medical or dental procedures so that any procedures such as surgery, childbirth or dental procedures that may result in bleeds can be managed in liaison with your Haemophilia Centre team
- Consult with your haematologist before taking medicines containing aspirin, non-steroidal anti-inflammatory drugs, and other blood thinners or supplements, herbal or homeopathic medicines that affect platelet function or clotting. This includes fish oil capsules with omega-3 fatty acids, and herbal treatment doses of ginkgo biloba, ginger, ginseng and chondroitin
- Ask your Haemophilia Centre for a treatment wallet card with your diagnosis, recommended treatment and who to contact in an emergency. Keep it on hand and show it to your other doctors or dentist and ask them to liaise with the Haemophilia centre team.

Adapted from:

Haemophilia Foundation Australia. Living with mild haemophilia: a guide. Melbourne: HFA, 2011. www.haemophilia.org.au

HFA WOMEN'S PROJECT

HFA is continuing with its work to develop some information resources for women with bleeding disorders. These will in a magazine style and will include the personal stories of women who have a bleeding disorder, including those who carry the haemophilia or VWD gene.

Jo's story about carrying the haemophilia gene in this issue of *National Haemophilia* and Haemophilia Foundation Australia's 2003 Women and Bleeding Disorders survey and interviews all highlight how important it is for women to connect with each other by sharing their stories and realising that they are not alone in their experiences – and that having a bleeding disorder is something that can be talked about.

You may have noticed that the new HFA booklets on haemophilia, mild haemophilia and von Willebrand disorder include special sections for women. These have been written with the input of Australian women with bleeding disorders in the HFA women's resources review group. They cover the messages that the women think should be communicated and brief information on relevant topics. The two most recent resources also include quotes from women.

There will be two new resources:

- Carrying the gene (haemophilia and VWD)
- Living with bleeding symptoms.

HOW TO BE INVOLVED?

If you are a woman who carries the gene or have bleeding symptoms and are interested in being involved, you can:

- Participate in the HFA women's resources review group. This involves contributing ideas on what should go in the resources and reading over drafts of the resources and giving your comments
- Tell your story and have it included in the new resource (and National Haemophilia) – it can be anonymous if you prefer – and you can write your story yourself or be interviewed over the phone.

If you would like to be involved please contact Suzanne O'Callaghan, Policy Research and Education Manager, Haemophilia Foundation Australia:

socallaghan@haemophilia.org.au, or
phone 1800 807 173

Dr Rachel Bushing is a Research Assistant at Queensland Haemophilia Centre

QUALITY OF LIFE ASSESSMENT – QUEENSLAND HAEMOPHILIA CENTRE

Rachel Bushing

ABOUT THE PROJECT

In mid-2011, the Queensland Haemophilia Centre (QHC) at Royal Brisbane and Women's Hospital invited all people with moderate or severe haemophilia A (factor VIII deficiency) or haemophilia B (factor IX deficiency) and who are clients of the QHC to participate in a Quality of Life survey. This exciting study was one of the first of its kind for the population of people with bleeding disorders in this region. The overall results of the study were to help inform the Queensland Haemophilia Centre to better understand the difficulties facing our clients, and importantly – to then provide better services.

The research was funded via a grant from Haemophilia Foundation Australia, and ethics approval was granted by the Royal Brisbane & Women's Hospital Human Research Ethics Committee.

An information pack was sent out to all adult clients who are over 18 and have moderate or severe haemophilia, and we received a high response rate with 64 questionnaires returned.

The Haem-A-QoL was chosen as the primary measure of interest as it has good reliability (ranging from 0.74-0.88), and high convergent (with SF-36), and discriminant validities. Moreover, it is specifically designed to capture aspects of Quality of Life for adult patients with haemophilia. Attempts to secure a scoring template for the Haem-A-QoL proved to be challenging. A general Demographics Questionnaire was developed for participants in conjunction with the Haem-A-Qol to capture relevant data for the exploratory analyses.

In conjunction with the Haem-A-QoL, the Demographics Sheet sought to identify whether Quality of Life (QOL) was dependent upon a number of variables including age, and the remoteness of the patients' residence. Exploratory analyses were conducted on a range of other demographical variables including employment status/

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ethnic-background/gender etc, to determine any other significant associations with overall QOL.

The project was advertised in the Haemophilia Foundation Queensland Newsletter and those who didn't initially respond were re-contacted to optimise response rates. As completed questionnaires were received, all de-identified data was entered into a statistical package in preparation for analysis. A comprehensive report of the project was drafted at each stage of the process, and a final report has been developed by the QHC.

WHAT IS QUALITY OF LIFE?

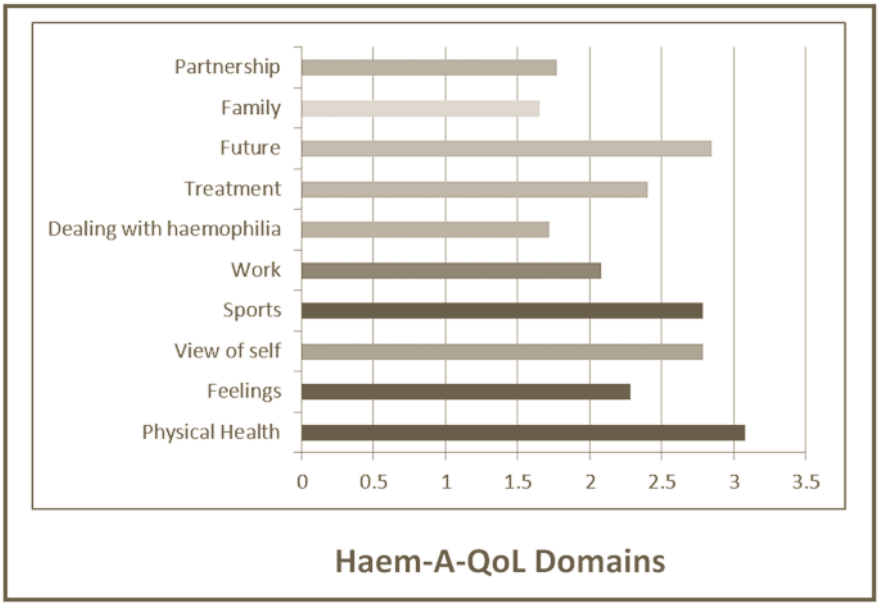
Quality of Life (QOL)

"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"[1]

Quality of Life has been investigated and reported on for a number of health conditions over the past 30 years. The research has shown that QOL assessment is especially helpful for individuals with chronic illnesses such as haemophilia because it measures specific health-related factors that might affect a person's way of life. In order to evaluate the effectiveness of haemophilia services, we can assess all aspects of a patient's health and wellbeing, including their life satisfaction, the degree of support they have around them, and how well they are able to get about with their daily tasks. Knowing a patient's perceptions of their health can ultimately help us to optimise their care. These patient-reported outcomes can be more meaningful than knowing about changes in a person's medical status, in terms of what their needs are and how we can best meet them.

WHAT DID THE STUDY TELL US ABOUT THE QUALITY OF LIFE OF HAEMOPHILIA PATIENTS IN QUEENSLAND?

- The areas in which patients experience the most impact upon their Quality of Life are: PHYSICAL HEALTH, VIEW OF THEMSELVES, SPORTS & LEISURE and THOUGHTS ABOUT THE FUTURE. These areas should be explored with our patients to see if we can make improvements. The results for each domain of the Haem-A-QoL are depicted in the graph below.
- Older patients have poorer Quality of Life in the area of PHYSICAL HEALTH. However, in general, Quality of Life was not impacted upon by a person's age.



- A similar Quality of Life was reported by patients regardless of whether they live in large cities, small towns or more remote localities.

We got some insight into particular problem areas for our patients, as well as areas in which they are doing well…

THE PROBLEMS	THE POSITIVES
• 40.7% had to refrain from sports that they like	• 27.0% of patients felt that haemophilia was "never" a burden for them
• Only 50.9% of patients could participate in work or school like other healthy colleagues "all of the time"	• 41.7% of patients said they were "never" dependent on physicians for treatment of their haemophilia
• Almost ¾ of patients felt they were dependent on factor concentrate "often" or "all of the time"	• ¾ of people reported no significant impact of haemophilia on their personal relationships or plans for children
• 57.1% of patients had pain in their joints "often" or "all of the time" in the last 4 weeks	• 58.1% of patients stated that they "never" felt excluded by others
• 50.0% said their life plans are influenced by haemophilia "often" or "all of the time"	• 39.0% said they were "never" interrupted in their daily activities by injections

- There was positive feedback for the QHC, with 57.4% of patients stating that they are satisfied with the Centre "all of the time", and 27.9% were "often" satisfied with the Centre
- Patients with SEVERE haemophilia (clotting factor activity levels less than 1%) had poorer Quality of Life than those patients with MODERATE haemophilia (clotting factor activity levels between 1-5%).
- Patients who reported their health status as poorer also reported experiencing worse Quality of Life
- Those who had been hospitalised over the past 4 weeks had poorer Quality of Life than those who had not been hospitalised
- There was no difference in Quality of Life among patients treated on-demand compared to those receiving prophylaxis
- A person's educational level, employment status, living arrangements and ethnicity did not have an impact on their Quality of Life.

WHAT DO THESE FINDINGS MEAN FOR PATIENTS OF THE QHC?

The QHC is committed to providing the best possible quality care for our patients. The study has shown us that aspects of QOL are important to understand in our patients, and it is likely that we will follow-up on this research by incorporating QOL measures in our clinical consultations. The past research on QOL indicates that those with better coping skills and a more positive outlook on their life circumstances may have better psychological adjustment when it comes to managing their haemophilia. By looking at a patient's QOL, we can target psychosocial interventions for patients which may have a greater need of these adjunct treatments. Understanding QOL for patients can help inform a broader clinical picture and aid in a more meaningful clinical discussion during consultations.

WOULD YOU LIKE TO FIND OUT MORE?

If you would like to discuss the results of this research in further detail, please contact the Queensland Haemophilia Centre.

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Associate Researcher – Ms. Maureen Spilsbury

Research Assistants - Dr. Rachel Bushing, Michelle Engels & Sara Jones

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REFERENCES

1. The WHOQoL Group. The development of the World Health Organization Quality of Life Assessment Instrument (the WHOQoL). In J Orley and W Kuyken, eds. Quality of Life assessment: international perspectives. Heidleberg: Springer-Verlag, 1994.

THE VISION AND LEADERSHIP AWARDS

The Vision and Leadership Awards were established by Haemophilia Foundation Australia (HFA) in 2007 to help people affected by a bleeding disorder to seek and achieve new goals. The Awards program is funded by an education grant from Pfizer Australia. People affected by haemophilia, von Willebrand disorder and other rare inherited bleeding disorders of all ages are eligible to apply.

This is a chance to do something you have always wanted to do if only you had the funds. It could help you reach a personal goal or complete an education activity or special project to improve your life. Or it might give you a chance to develop leadership skills to support your voluntary work in the bleeding disorders community.

What would make a difference in your life? Consider applying for one of these Awards to help you achieve success or reach a new goal or objective in 2012.

- Up to five Awards of $2,000 each for applicants in either of the following categories will be available:
- Young men and women aged 15-25 who have a bleeding disorder or who are affected by bleeding disorders
- Adults aged 26 years and over (men or women) with a bleeding disorder or who are affected by bleeding disorders

APPLICATION TIMEFRAMES AND DEADLINE

The 2012 funding round is now open and will close on 20 May 2012. Winners will be announced in *National Haemophilia* and on the HFA web site www.haemophilia.org.au .

Closing date for applications

20 May 2012

Assessment process

A panel has been established by HFA to consider applications and monitor the Awards program.

How to Apply

Your application must be on the Vision and Leadership Application Form. Download the form from the HFA website www.haemophilia.org.au or request a copy from HFA. Applications must be received by email, post or fax to HFA:

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

MAKING A DIFFERENCE

"Australia really is the lucky country.

While we worry about things like what should we eat for dinner or what size television we should get next, a lot of people in Southeast Asia don't have that sort of luxury; in fact they don't have any luxury at all. I had an epiphany in 2008 while doing some volunteer work in an orphanage in Angkor Wat (even though I'd done charity work in Southeast Asia before) and from that time on my wife and I have been planning the long term vision of moving to Southeast Asia and doing volunteer work to assist the local people, especially the kids.

We intend to also couple this with doing work with the haemophilia foundations in their respective countries. To assist in this goal, I decided it would be beneficial to complete a Teach English as a Second Language (TESOL) course and was saving to start one. In October 2011 I decided to apply for a Vision and Leadership Award and was a lucky recipient of one of the grants. The money was put straight into the course and I'm (albeit slowly) working my way through the course. Without the grant I probably still wouldn't have started the course.

If you have a dream or passion why not put an application in for this year's Vision and Leadership Awards?"

Ian Lim, 2011 Vision & Leadership Award Recipient

HIV FUTURES SEVEN SURVEY EXTENDED -

WWW.HIVFUTURES.ORG.AU

The deadline for the HIV Futures Seven survey has been extended to 1 April 2012.

Take this opportunity to contribute and have the experiences of people with bleeding disorders and HIV included in the national study!

Futures is a national anonymous survey on the experiences of people living with HIV in Australia, including their health, treatments, social life, work and financial situation. It is an opportunity for people with bleeding disorders and HIV to give data on their particular experience for a national evidence-based study.

The survey results are provided to PLHIV, community organisations, service providers, doctors and government. The survey is being conducted by the Living with HIV program at the Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.

Hardcopy survey booklets are available from HIV organisations, in some Haemophilia Centres and from HFA. The survey can also be filled out online - www.hivfutures.org.au.

More information:

HIV Futures – Living With HIV Program

T: (freecall) 1800 064 398 or

E: hivfutures@latrobe.edu.au

NEW GRANT PROGRAM FOR HEALTH PROFESSIONALS

A new grant program launches this April to provide funding to members of multidisciplinary haemophilia care teams in Australia, including nurses, physiotherapists, psychologists and social workers.

The 'Changing Possibilities in Haemophilia' Grant, supported by Novo Nordisk, will offer funding for new practical initiatives or programs that seek to advance haemophilia care in Australia. An independent professional panel, representing a range of healthcare disciplines working in haemophilia, together with the Haemophilia Foundation Australia, are involved in the initiative and will judge the applications.

The initiative will formally launch on World Haemophilia Day – 17 April 2012. It is open to healthcare professionals based and working in Australia.

More information and application forms are available from www.changingpossibilities.com.au.

The closing date for applications is 31 July 2012.

Recipients of the Awards will be announced during Haemophilia Awareness Week in October 2012.

CALENDAR

World Haemophilia Day
17 April 2012
www.wfh.org

WFH Congress 2012
8-12 July 2012 – Paris, France
World Federation of Hemophilia
Tel.: +1 (514) 875-7944
Fax: +1 (514) 874-8916
Email: info2012@wfh.org
www.wfhcongress2012.org

Haemophilia Awareness Week
7-13 October 2012
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

XXXI International Congress of the World Federation of Hemophilia
Melbourne, Australia 2014
www.wfh.org

Wear RED on World Haemophilia Day
www.haemophilia.org.au

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