National Haemophilia

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WORLD HEMOPHILIA DAY / APRIL 17

BUILDING A FAMILY OF SUPPORT

WORLD HEMOPHILIA DAY 2015 | APRIL 17

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WORLD HAEMOPHILIA DAY

6.9 million people worldwide have a bleeding disorder. 75 percent of them do not know it.

BUILDING A FAMILY OF SUPPORT

Every April 17, World Haemophilia Day is marked worldwide with the goal of increasing awareness of haemophilia and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH) who chose to bring the community together on April 17 in honour of WFH founder Frank Schnabel's birthday.

World Haemophilia Day 2015 is focused on the importance of **Building a Family of Support.** It is crucial that those with a bleeding disorder build a family and network to provide encouragement and care for them. As well a strong family and network can contribute to advocating for awareness and better **Treatment for All.**

A significant amount of care, support, and advocacy is done through extended families which come in many forms: medical teams, friends, and colleagues, as well as immediate relatives. These communities share the ability to come together in large numbers and encourage the improvement of the lives of people with a bleeding disorder.

There will be special activities for our online community, so be sure to follow these Facebook pages for details on World Hemophilia Day news and activities:

- WFH Facebook page - www.facebook.com/wfhemophilia
- HFA's Facebook page - www.facebook.com/HaemophiliaFoundationAustralia
- AAMI Park in Melbourne will light up red to commemorate this special day, with many landmarks across the world doing the same.

MAKE A FAMILY TREE

Make a family tree on World Haemophilia Day. For a template and how to guide visit tinyurl.com/makeafamilytree.

World Haemophilia Day 2015 will be a unique opportunity to connect with the global bleeding disorder family on the World Federation of Hemophilia social media network and encourage your online community to join the global family!

For information and resources visit: www.wfh.org/whd.

BUILDING A FAMILY OF SUPPORT

Join us on April 17 to raise awareness about bleeding disorders and the need to build a family of support for those living with them.

Families come in many forms but they all share the ability to support and advocate.

WORLD HEMOPHILIA DAY **2015** | **APRIL 17**

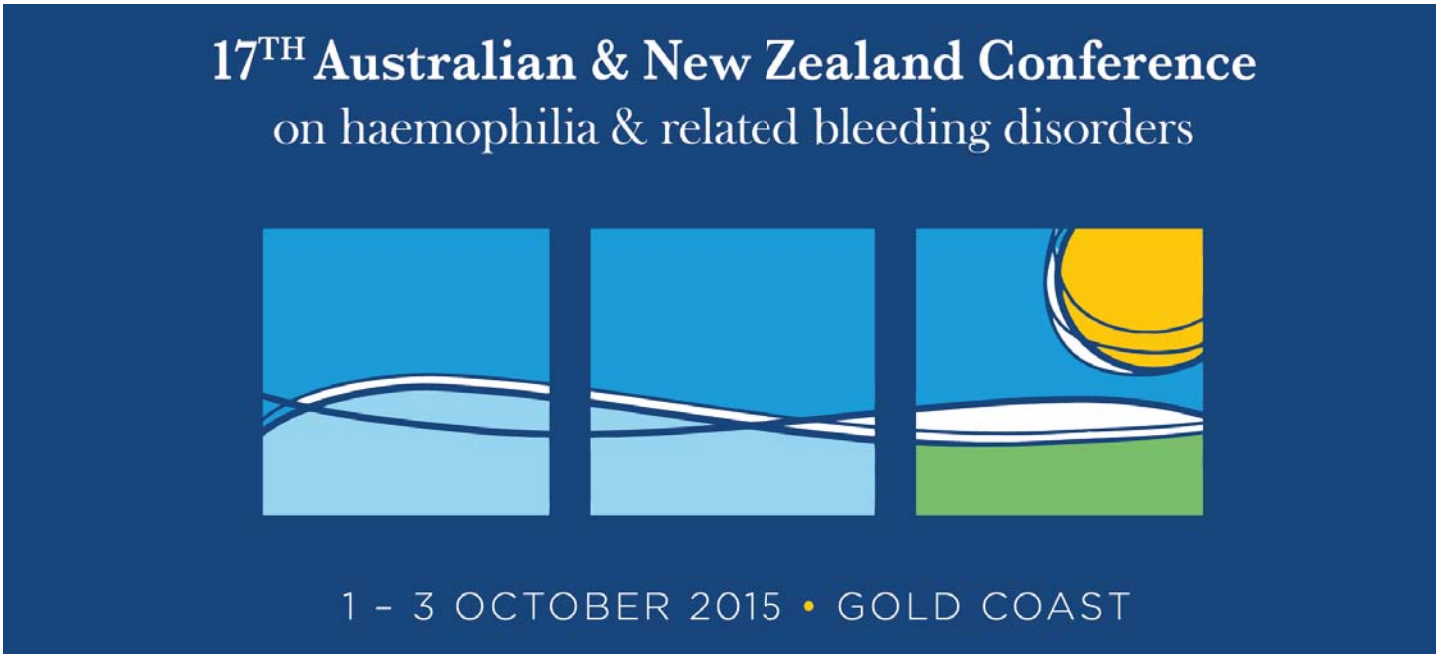
wfh.org/whd

facebook.com/**wfhemophilia**

@wfhemophilia
Follow the latest World Hemophilia Day development at #WorldHemoDay

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

2015 HAEMOPHILIA CONFERENCE



The 17th Australian & New Zealand Conference on Haemophilia and Related Bleeding Disorders will be held at the QT Hotel, Gold Coast 1-3 October 2015.

After the very successful World Congress in Melbourne in 2014 we look forward to a stimulating and exciting Australian & New Zealand Conference to discuss and debate issues and follow up on ideas and connections made.

If you attended the Congress, you will love the Conference in October. If you missed the Congress you will have a chance to catch up. For all stakeholders in the bleeding disorders community it will be a chance to meet up again, renew friendships and learn more about living with bleeding disorders or managing them regardless of your role and interest.

The venue has good access in and around the hotel and on the conference floor. The conference area does not involve long walking distances, and the hotel is suitable for people who use wheelchairs.

Planning for the Conference is well under way.

Earlybird registration closes 31 July 2015.

For more information visit www.haemophilia.org.au/conferences.

Multidisciplinary Program
The program has topics and issues to interest everyone including the following and more:

- Living well with bleeding disorders
- Best practice treatment and care and how this is measured and monitored
- Supply and safety of treatment products, including long acting clotting factors
- Family planning
- Youth matters
- Helping children live with a bleeding disorder
- Improving your joints
- Women's health and bleeding issues
- Understanding von Willebrand disorder
- Managing pain
- Hepatitis C treatment and care – including new treatments
- Living well with HIV
- The global bleeding disorders picture

The program will include people living with bleeding disorders as experts as well as health professionals and others presenting from different perspectives.

Who should attend?
- People with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners
- Health professionals – doctors, nurses, physiotherapists, social workers/counsellors and other health care providers
- Treatment product producers, suppliers and service providers

- Policy makers and government officials
- Haemophilia foundation volunteers and staff

Abstracts and Posters
We are calling for abstracts. Abstracts may be accepted for a presentation in the main conference program or included as a Poster in the Poster Exhibition.

We encourage abstracts relevant to clinical practice and care, laboratory science, research, policy or living with bleeding disorders or treatment complications.

See www.haemophilia.org.au/conferences for the abstract submission form and more information. There will be prizes for the Best Abstract, and the Best Poster.

Submit your abstract by Friday 5 June 2015.

OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

The annual meetings of **specialist health professionals' groups** will be held on Thursday 1 October 2015:

- Australian Haemophilia Centre Directors' Organisation
- Australian Haemophilia Nurses Group
- Australian Haemophilia Social Workers and Counsellors Group
- Australian & New Zealand Physiotherapy Haemophilia Group
- ABDR Data Managers Group.

Workshops
Watch out for more information about special workshops on selected topics that might interest you during the Conference.

Welcome and Exhibition Opening
Join us on Thursday evening at the official opening of the exhibition and welcome to the Conference. This is complimentary to all registered delegates.

Men's Breakfast & Women's Breakfast
The breakfasts have always been popular and give an opportunity for men and women to meet and share their experiences – speakers not yet confirmed, but they will be interesting and relevant!

Youth
Youth activities will be organised throughout the Conference and the program will have sessions of interest to young people integrated throughout the program over the Friday and Saturday. Additional activities for young people will be organised and we will advise youth who have registered once the final program is confirmed.

Remembrance Service
A Remembrance Service is a very special time during our Conference to remember friends and family, and the people we have cared for in our community, who have died. The service is non-religious and everyone is welcome. It will be held on Friday 2 October before the Conference Dinner.

Conference Dinner
Join us for a relaxing and casual night with other delegates for the dinner on Friday 2 October 2015.

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

In my role as President of HFA I am often asked about what HFA does, what the role of the HFA Council is and what I and other HFA volunteers do as part of that.

So, in this edition of *National Haemophilia* I thought it would be a good time to talk about the governance of HFA and how things work. There are many "cogs in the wheel", and it is really important that everyone plays a part so things come together.

HFA COUNCIL
The Council is the governing body of HFA. It is made up of Delegates from each of the State/Territory Foundations. So, when we talk of members there are actually two levels. HFA's members are the State/Territory Foundations, the actual organisations, while the members of the State/Territory Foundations are the individuals and families who join the Foundation in their state/territory so they can participate in their local activities. These activities might range from regular camps and peer support workshops to education bursaries and subsidies, and other support to their local members depending on the policies of the local Foundation and its capacity to offer support.

An important part of a local Foundation's work is to ensure the needs of the bleeding disorders community are well represented and responded to at a state/territory level and this may result in local advocacy and representation. This advocacy/representation might include advocating for Haemophilia Treatment Centre services or state government funding to support the State Foundation and its services.

One of the most important ways a local Foundation is involved in HFA is the role their Delegate plays on the

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We often run short surveys and invite people to participate via the HFA website, facebook and enews.

It's important that we know what you think and what your needs are, so please feel free to have your say.

HFA Council. Council sets the policy direction of HFA and determines its plans and priorities. The HFA staff team, led by Sharon, then works to put these into effect. So it is really important that the local Foundation Delegate can represent the local Foundation as well as wear a "national hat" representing what we do for the whole of our bleeding disorders community.

ADVOCACY AND REPRESENTATION

It is important that HFA represents the needs of the community, and is accountable to its membership – ie the local Foundations. So, the issues HFA deals with are usually generated from concerns and ideas that work their way up from the local Foundation to HFA. These issues can be addressed from a broader point of view, drilling down on behalf of everyone with bleeding disorders or parts of our community.

This might lead to advocacy and representation to federal members of parliament, federal government bodies or committees for treatment and care, and to education and peer support programs developed by HFA. Examples of this are the national youth camps and leadership training, national conferences, education materials available in print and on the HFA website.

HFA relies on a network of relationships and sometimes quite strategic alliances with other stakeholder organisations in the blood sector and other areas which provide family and disability support, treatment and care. Sometimes HFA asks very specific questions – you will have noticed we often run short surveys and invite people to participate via the HFA website, facebook and enews. We can ask specific questions about specific topics that inform our policy or representation. HFA plan to run a large national survey in June on a range of topics so we can make sure we are keeping up on the issues people are concerned about.

THE NEW HFA COUNCIL

The changes to the HFA Constitution last year were made with a view to a closer engagement between HFA and local Foundations and quicker decision making. Each member Foundation will have just one Delegate on Council (previously the larger states had two) and that person will usually be a key leader at local level who will be able to support the communication back and forth from HFA, local Foundation and vice versa so we can make more timely decisions.

HFA STAFF AND OFFICE

HFA is set up with staff and resources to look after things like writing submissions, liaising with other national bodies and organisations, researching and developing education resources to save local Foundations having to "re-invent the wheel". HFA also provides logistical support to Foundations, and to states that do not have a Foundation and the capacity to represent their community.

HFA also coordinates national awareness campaigns, national conferences and runs a national fundraising program to help all local Foundations. Through the National Fundraising Program, HFA staff make applications to philanthropic trusts for local projects and activities around Australia. This includes funding for some of the camps and peer support workshops that local Foundations run for their members. This is getting tougher and tougher and we are trying different ways to achieve success in this area.

HFA PRESIDENT

So what do I do? I am the President of HFWA and the HFWA Delegate to the HFA Council. My role as Delegate is as I have already described. However, Council has also elected me as President of HFA and it is my honour to serve the community in that role. As the HFA President my role is to ensure we do things properly, that we include the right people in our decision making and that we meet our statutory and regulatory obligations and that we represent and report appropriately to our members. I am often the "public face" of people with bleeding disorders and attend meetings on behalf of HFA to represent the concerns of interests of our members. For example, I recently appeared before the House of Representatives Parliamentary Committee on Health to describe my own experience of hepatitis C and that of others in our community.

BEING PART OF HFA

But it is a team effort – our local Foundations, our volunteers at both local and HFA level and our staff are critical to our successes. And beyond that our stakeholder relationships are important, including those with our Haemophilia Centres and treating health professionals.

How can you be involved? Our aim is to represent our community in the best and most professional way we can. But if we are to be the collective voice of the community, it's important that we know what you think and what your needs are, so please feel free to have your say. Talk to your Foundation and your Delegate, answer our surveys, tell us your point of view - ring us or email us, if you prefer. We're always open to suggestion and keen to know what's important to you.

The section of this article on Cambodia is adapted with permission from "Twinning connection", published in *Bloodline*, the newsletter of the Haemophilia Foundation of New Zealand (www.hfnz.org.nz), December 2013 and December 2014.

TWINNING PROGRAMS

THE EXPERIENCES AND CHALLENGES OF 3 PHYSIOTHERAPISTS

The importance of physiotherapy has been widely established as being integral to the management of haemophilia. This is the case both in haemophilia treatment centres where there is access to adequate factor replacement, and in centres where factor replacement is limited. Physiotherapists who are experienced in delivering physiotherapy for people with haemophilia, and its related musculoskeletal issues, are now being included in the care teams of medical professionals involved in the haemophilia treatment centre twinning teams.

Three haemophilia physiotherapists from Australia and New Zealand who have been involved in haemophilia treatment centre twinning in in Vietnam, the Philippines and Cambodia comment on their experiences and challenges.

The **Twinning Program of the World Federation of Hemophilia (WFH)** was established more than 15 years ago. This program aims to improve haemophilia care in emerging countries through a formal, two-way partnership between two haemophilia organisations or treatment centres for a period of four years. Twinned organisations or haemophilia treatment centres work together and share information, resulting in a mutually beneficial partnership. It is a great way to transfer expertise, experience, skills, and resources.

The WFH has two types of Twinning Programs:
- Haemophilia Treatment Centre Twinning
- Haemophilia Organization Twinning

Haemophilia Treatment Centre Twinning:
The Haemophilia Treatment Centre Twinning (HTC) Program partners emerging HTCs with established ones to help improve diagnosis and medical attention for people with haemophilia.

Source (adapted): www.wfh.org

VIETNAM

Abi Polus, Senior Clinical Physiotherapist – Haemophilia, Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

The Ronald Sawers Haemophilia Centre (RSHC) at The Alfred Hospital, Victoria, is twinned with the National Institute of Haematology and Blood Transfusion Centre (NIHBT) in Hanoi, Vietnam.

In 2012 I visited NIHBT Hanoi, Vietnam, my first experience of the twinning program. A nurse and doctor had gone the previous year to establish a relationship with the Vietnamese team and work together in deciding what would be of benefit. It was an eye-opening experience for me.

On my first day I worked with the medical staff and physiotherapists from the northern half of Vietnam. I had been asked to tailor a program on the importance of physiotherapy in haemophilia. I gave lectures where I discussed the role of physiotherapy and the need to be active and exercise, even in the environment where very little, or no factor is available. In particular, I discussed the importance of rest after a bleed, and thereafter regaining range of motion, and strengthening muscles to support joints. These were concepts that many of the medical teams and physiotherapists were unaware of. Haemophilia is a haematological (blood) disease; in Australia we have been very fortunate to have relatively recent access to the specialists trained in musculoskeletal management of the manifestations of the disease. In some areas of the world this has not been identified or resourced at this stage. I have only been in my role since its inception in 2010 and I found it immensely humbling and rewarding to be able to pass on my experiences in setting up a service and the knowledge I have acquired.

I then ran two days of practical workshops where Vietnamese patients presented to me in front of an audience of around 50 physiotherapists, and I discussed and demonstrated how I would assess these patients to determine the musculoskeletal issues and determine the appropriate course of management. At that time very few patients with haemophilia ever got to see a physiotherapist, despite their extensive joint destruction. By providing information about what physiotherapists could offer patients, this was something that I hoped to change.

We also participated in a hospital ward round with the Vietnamese medical team and saw how they managed their haemophilia patients in hospital. My background of working in an adult hospital where access to factor replacement is widely available without cost to the patient meant I have not seen patients with such degrees of deformity at young ages. In Vietnam I saw young adults and children with large, swollen target joints and end-stage joint destruction were unable to move or walk. Many of the contractures (fixed bend) in hips and knees

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were irreversible and will cause permanent disability. It makes me appreciate how lucky we are to have the medical care that we have, in addition to the access that we have to factor replacement agents. It also highlighted the difference that access to gait aids such as crutches, and early and gentle exercise can make. These patients can receive cryoprecipitate, but it is not as effective, and decisions may be made on what the patient can pay for. Lack of finances also restricted patients from presenting with bleeds that we would usually see early and there was little access to pain relief. Patients who had had huge bleeds and who needed crutches or wheelchairs did not have access to them and had to crawl, be carried, or walk on a very painful limb. I asked one child if he had crutches? "I do", he told me proudly. "Big ones. I am just waiting until I grow into them!"

What I also found very sad was the presence of three patients on the ward who had spinal-cord injuries with irreversible paralysis of arms and legs, whilst seeking traditional Vietnamese treatments such as massage, cupping and acupuncture around the neck and back spinal cord. These treatments had caused them to bleed around and damage central nerve tissues permanently. It is largely avoidable (by abstaining from such treatments) but unfortunately, lack of knowledge has caused these catastrophic and irreversible injuries.

The people I saw did not complain of pain; they had the most amazing resilience and just got on with life. They really were inspirational.

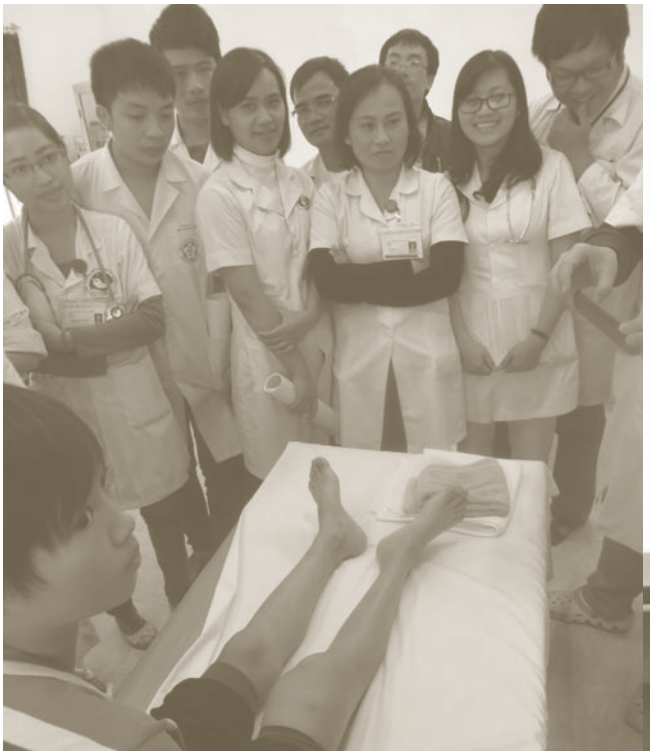
In 2013, prior to our visit, we found out that our centres had won the 'Haemophilia Treatment Centre Twins of the Year' for 2012. This was a big honour and was very rewarding, especially coupled with returning and seeing how the Vietnamese team and our Centre had worked so well together and progressed forward.

At the end of 2013 I returned to Hanoi where I worked with the rehabilitation teams with further workshops and lectures. I also gave a talk to the patients and their families. It appeared that most of the patients had not previously had the opportunity to learn why haemophilia affects joint and muscles and the connection between bleeds and the musculoskeletal issues that they experience. For me the highlight of this trip was witnessing their immediate understanding, and being asked question after question that demonstrated they had understood and wanted to know more.

After two and a half days in Hanoi it had been arranged for us to go down to the south of Vietnam to Ho Chi Minh City (HCMC) as the patients and team in Hanoi had seen the benefits of working together with the twinning teams. As a result they planned to roll out the twinning program to the rest of the country, and we repeated some of the program in HCMC. The haemophilia patients in HCMC are in the general hospitals and a tour of the children's and adult hospitals there was even more eye-opening than what we had seen at the NIHBT hospital in Hanoi. The overcrowding was apparent; patients were lined up, sometimes three to a bed with a central drip stand in the middle. It was swelteringly hot and humid, and mothers worriedly fanning listless babies. The problems with the prohibitive distances and travel costs that patients had to overcome to in order to present to hospitals in the first place, and the cost of treatment were also apparent.

Being part of the twinning program has been a very humbling experience. The Vietnamese doctors, physiotherapists and other members of the haemophilia team work extremely hard and are extremely resourceful with what they do have and were eager to discuss how to improve services. It has made me extremely thankful for the health system that we have here (warts and all!).

Twinning visits to Vietnam 2012 and 2013



Davao Twinning visit 2014

PHILIPPINES

Wendy Poulsen, Haemophilia Physiotherapist, Lady Cilento Children's Hospital, Brisbane

The Queensland Haemophilia Centre is twinned with Brokenshire Hospital in Davao, the Philippines

The visit to the Philippines in July 2012 was a follow up from an initial visit done the previous year by Dr John Rowell from the Queensland Haemophilia Centre and Beryl Zeissink, the adult haemophilia nurse. They were able to establish initial contact with the appropriate health professionals in Davao, finding out how haemophilia was managed, how many patients were registered, and essentially the resources that were available. From this initial visit they were able to establish that there was a need for education on haemophilia to medical staff and training for nurses and physiotherapists, to be done over a two day period.

On the first day of our follow-up visit, Beryl and I were taken to the Brokenshire Hospital, where we had a tour of the hospital and then we ran a haemophilia clinic in conjunction with the local consultants. We take so many things for granted in Australia. There was a tiny little room, no air conditioning and to survive in the heat, the husband of one of the consultants "bought" the additional electricity required for a fan to be used in the room.

We had the pleasure of meeting 10 young men aged from 4 to 20 and their families in this morning clinic. These families appeared to have limited financial support, and they were unable to pay for product, or even essential things like crutches and splints.

The first little boy that I met had been seen by Dr John Rowell on the previous visit. He was concerned that this young man had perhaps developed an inhibitor because he had not responded to treatment that had been given. He had been given a couple of treatments with factor VIII, but he had a persistent knee bleed. At Dr Rowell's suggestion to redo bloods, he was re-assessed and diagnosed with factor IX (9) deficiency. At the time of our visit, it had been confirmed that his factor deficiency was factor IX, and that his knee had made a full recovery.

I have been working in haemophilia for many years and can say that I have never met so many young men with debilitating joint and muscle conditions. It highlights the importance of a functioning multidisciplinary team, the use of factor for bleed management (and in the ideal world, even prophylaxis). I saw young men that had minimal joint movement and significant contractures, and I struggled to think how I could possibly help these young men, particularly with the minimal resources available. Suggestions of hydrotherapy, crutches, splinting, or a rehabilitation program just were not an option, as most of these families came from little villages located many miles from the treatment centre.

The next day we conducted an education seminar. This was attended by over 100 participants, including nurses, physiotherapists, an orthopaedic specialist, haematologists and physiotherapy students. The day's program consisted of an education session in the morning and then break-out groups of nurses and physiotherapists and others. Topics covered were an overview of haemophilia, understanding von Willebrand disease (VWD), standards of nursing care in haemophilia and physiotherapy management in haemophilia.

The afternoon session was an interactive and animated session providing hands on assessment, practical demonstrations of casting and exercise programs. We were fortunate to be able to demonstrate on "real" patients, some who had recently had a bleeding episode, and some who had significant musculo-skeletal issues as a consequence of multiple poorly treated bleeds. It once again highlighted the limited resources available, including health professionals with a working knowledge of bleeding disorders, that we accept as routine.

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Follow-up visit 2014
We did our follow up visit in July 2014. I travelled with Dr John Rowell and Maureen Spilsbury, the Senior Social Worker. Once again our visit was challenged by the weather, with a cyclone brewing off the coast.

The focus of this visit was to continue our education of haemophilia, but additionally to focus on the genetics of haemophilia, pregnancy and delivery, through family group sessions directed by Maureen.

My direction this visit was to work with the physiotherapists in the use of the Haemophilia Joint Health Score (HJHS) and its practical application with patients. Over 20 physiotherapists and 5 physiatrists (rehabilitation physicians) attended my session where I provided education on treatment interventions; back to basic evaluation of muscle function, and HJHS. The afternoon session was attended by 15 patients (aged from 5-55 years old). Because of the age variance and thus complexities of physical presentations, the use/benefit of the HJHS was identified. In some cases the HJHS was not useful because of the physical limitations of the patients. It highlighted that good musculoskeletal assessments carried out by physiotherapists provided more useful information for both therapist and patient. I was delighted to see the depth of knowledge that these local therapists have.

The next day was directed by Maureen who ran several family group sessions focusing on genetics and psychosocial issues. This was well attended by over 100 people, including families, patients and health care professionals.

Once again we were looked after beyond our expectations. We were picked up and delivered, we were overfed, and made to feel so welcome. We all look forward to our continued contact in Davao.

For the future
We need to continue our support of this country. Improved conditions for people with bleeding disorders will only get better with the provision of dedicated factor, and through support for the dedicated health professionals with their passion to care for this group of people who have had such devastating consequences from their bleeding disorder. The continued development of an up-to-date registry of patients continues to challenge, but is necessary for the overall management.

CAMBODIA

Colleen McKay, HFNZ Manager of Outreach Services, and Lee Townsend, Haemophilia Specialist Physiotherapist at Christchurch Hospital, New Zealand

Haemophilia Foundation New Zealand (HFNZ) is twinned with the Cambodian Hemophilia Association (CHA), Cambodia

In August and September 2013 HFNZ Manager of Outreach Services Colleen McKay and Haemophilia Specialist Physiotherapist Lee Townsend (Christchurch Hospital) travelled from New Zealand to Cambodia for a Twinning Visit.

The annual Twinning Visits are a really important part of the Twinning relationship. They provide a chance to get together in person to review how things are progressing, an occasion for further training and activities and an opportunity to make plans for further development.

Workshop for families
One of the main objectives of the Twinning Visit was to deliver a 1-day workshop for families in Phnom Penh, the capital of Cambodia.

The workshop, "'Physiotherapy for Hemophilia Patients" was held on Saturday 31 August at the Cambodiana Hotel in Phnom Penh. It was well attended, with 57 participants, including families with children with haemophilia.

Mr Rithy and Ms Tev Linat, volunteer Social Worker with CHA were in charge of communication with members to promote the event. The fantastic attendance and media coverage received was evidence of their success, including coverage on television and in newspapers.

After opening speeches from Mr Kong Sithan and Mrs Colleen McKay, HFNZ , his High Excellency Ung Sambath, Deputy Secretary of the Disability Action Council, a physiotherapist by training, gave an overview of disability in Cambodia and the law that protects the rights of people with disabilities. This was followed by Mr Song Sit, Chairman of Physiotherapy Association in Cambodia on the Cambodian Physiotherapy Association.

Lee Townsend, Haemophilia Specialist Physiotherapist from Christchurch also travelled with HFNZ to Cambodia to help educate families and health professionals about bleeding disorders. She discussed what happens inside a bleeding joint, how to recognise and treat a bleed, PRICE (Protection, Rest, Ice, Compression, Elevation) and the damage that can occur such as synovitis and arthropathy. She also discussed the importance of exercise and how it can help, especially when little product replacement is available. Lee was also able to assist with individual consultations for those with haemophilia alongside the local physiotherapists and recommend appropriate exercises in order to strengthen muscles and improve joint function.

The family workshop in Phnom Penh

After her presentation one patient commented that he now understood what had happened to his knee for the first time and why he is unable to bend his knee as much as he used to. He said he also understood that he would still be able to build up the muscles around the joint in order to keep his legs strong.

Other meetings

The Twinning visit was also an opportunity to meet with the Cambodian Hemophilia Association (CHA) Committee for training on how to succeed as an NMO and plan for the year to come.

HFNZ and CHA representatives also met with a number of stakeholder organisations and institutions including the National Blood Transfusion Center and Disability Action Council.

CHA and HFNZ congratulated the National Blood Transfusion Center on the success of their public blood drives. Due to these they had a supply of regular donors and an excess stock of Fresh Frozen Plasma. Although the Center had sufficient plasma to manufacture cryoprecipitate, they lacked the necessary equipment, trained staff and the room needed to begin. With the increasing number of new diagnoses of haemophilia there was a desire for Cambodia to manufacture cryoprecipitate in order to become self-sufficient in the treatment of those with haemophilia. At that time, the National Pediatric Hospital in Phnom Penh had a very limited stock of donated Factor VIII from the World Federation of Hemophilia (WFH). The manufacture of locally made cryoprecipitate would ensure that it was more likely that people with haemophilia in Cambodia would be able to have treatment for their bleeds. A plan was made to try to help source the necessary equipment and training for staff.

During their meeting with the Disability Action Council they discussed the important steps that had been achieved for those with haemophilia and the importance of access to physiotherapy. For example, haemophilia had been recognised and listed as a disability which gives people with haemophilia in Cambodia rights under the Law on the Protection and the Promotion of the Rights of Person with Disabilities.

The visit also included visits to two physiotherapy clinics – one at the National Pediatric Hospital and one at an NGO-run clinic, the Kien Khleang Rehabilitation Clinic which is run by Veterans International Cambodia. In contrast to the Physiotherapy Department at the National Pediatric Hospital which had very little equipment, the Rehabilitation Clinic was full of physiotherapy equipment and mobility aids. They were also well staffed with physiotherapists, orthotists and prosthetists. They established that this Center is where people with haemophilia requiring mobility aids such as crutches, wheelchairs, and walking frames should come to be fitted with when appropriate. The NGO provides this service and the aids free of charge.

Twinning visit 2014

In October 2014 Colleen McKay returned to Cambodia for the final HFNZ-CHA Twinning Visit, along with HFNZ Treasurer Grant Hook and Robert Leung from the World Hemophilia Foundation (WFH).

During the visit representatives of HFNZ and CHA met with the Director of the National Blood Transfusion Service in Phnom Penh. The US Embassy Department of Defence is supporting a new building for the National Blood Transfusion Service and as part of this project funding is secured for the equipment required to manufacture cryoprecipitate – an important move forwards for Cambodia to be able to provide a treatment product for their patients. Production of cryoprecipitate is expected to start by early 2015.

This final visit was also a time for HFNZ and CHA to work on structuring CHA's plans over the next two years. Together with Robert Leung, they also discussed the ways that WFH can assist CHA move forward into this next stage of their development.

It was heartening for HFNZ to be involved in Twinning with CHA and see how they have developed as an organisation over the course of the Twinning Programme. They have a strong core of committed volunteers and many plans for people with haemophilia in Cambodia. Strong bonds have definitely developed between HFNZ and CHA and people with haemophilia in Cambodia will maintain a special place in the hearts of HFNZ members.

To see more about Twinning in Cambodia, see the CHA Facebook page (search for Cambodian Hemophilia Association) or visit the CHA website www.chacambodia.org.

Sharon Caris is Executive Director,
Haemophilia Foundation Australia

GOING ON HOLIDAYS?

Travelling is a wonderful opportunity for seeing new places and adventure but it can be much more enjoyable if you are prepared for all eventualities..

Sharon Caris

PLANNING TRAVEL AND HOLIDAYS!
If you are going interstate or overseas for holidays you need to be organised to be sure you have arrangements in place. Don't forget to start your planning early with your Haemophilia Centre to ensure you have sufficient clotting factor and equipment, other medicines and letters from your doctor to take with you. If you are going overseas make sure you have the necessary medical, customs and quarantine documents for your treatment product and equipment, both for leaving and returning to Australia and for entering the countries you are visiting. Even if you are in transit through a country, remember there may be documentation requirements to carry your clotting factor, needles and other medicines through security/quarantine/customs at airports.

Make sure you select carefully where you will travel, especially if you might need medical assistance. Check whether there is expertise in the care and treatment of people with bleeding disorders in the places you are visiting, and how you would access these services. Be aware that treatment may be limited, unavailable or unaffordable in many countries. Make sure you have appropriate travel insurance and a plan in the event that you have a bleed or have an accident. And contact where you will be staying to find out if you will have access to a refrigerator (so you can keep your medication cold).

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

Make sure you contact your Haemophilia Centre staff well in advance so they can help you with your travel plans – especially for ordering supplies of clotting factor and the necessary documentation required during your travel. HFA can also provide more information about your planning for overseas travel.

This article is adapted with permission from an article published in *The H Factor*, newsletter of Haemophilia Foundation Queensland (www.hfq.org.au), Spring 2014.
Sarah Hartley is a Board Member of Haemophilia Foundation Queensland

TRAVELLING — in the USA

Sarah Hartley

Our family of four recently returned from a trip to Hawaii and Los Angeles. My husband and I travelled with our two sons, aged 9 years and 18 months. Our eldest son has severe haemophilia so we had to 'factor' in a few extra things like securing travel insurance for an existing medical condition, flying internationally carrying needles and clotting medication, refrigerating medication while staying in various hotels and infusing on the run.

We visited Waikiki Beach in Hawaii which was balmy and very festive, we swam at a waveless beach - we thought we'd leave the 60 foot waves to those fearless surfers! In Los Angeles we did some star spotting at the Hollywood Walk of Fame, played some air guitar at the Hollywood Hard Rock Cafe and strolled along Rodeo Drive in glamourous Beverly Hills. We cheered along at a baseball game at Dodgers Stadium. My husband and son scored a few touchdowns playing Grid Iron football together at Newport Beach. Disneyland really was the 'Happiest Place on Earth' for us and we all had a great time exploring the different 'lands' and experiencing some very high-tech and exciting rides.

TRAVEL INSURANCE

I travelled to the USA with my son four years ago and ran into the problem of securing travel insurance for an existing medical condition like haemophilia. At that time we had success with one company who provided our son with medical cover for haemophilia-related issues for an additional fee. However, our application for cover with them this time was unsuccessful. We tried other companies and got the same result.

We finally had success with a different company who provided our son with unlimited medical cover for any haemophilia-related issues for an additional fee of approximately $200. We thought this was a good deal for us considering the potential cost of admission to hospital in the USA. Fortunately our son had no bleeds overseas and did not need any hospital treatment.

FLYING WITH FACTOR

The Haemophilia Centre at the Children's Hospital provided us with a letter we could present to authorities if we had any trouble getting through airport security with our needles and clotting medication. The airlines like people to keep any medication nearby in case of a medical issue in flight, so we had to take the factor on board in hand luggage. The airline had no space to refrigerate medication in flight. We had the factor packed in with ice packs however by the end of the flight (9 to 10 hours later) the ice packs had melted so the medication was still cool, but not cold anymore.

REFRIGERATION OF FACTOR

Fortunately all the hotels we stayed at had small in-room refrigerators so the medication was kept cold - with the exception of the hotel in Los Angeles, where first the fridge had a meltdown and ceased to work, then I had a meltdown when I realised all the medication was no longer cold or even cool. My husband raced down to the reception desk and requested a replacement fridge and was told yes, he also asked if there was a fridge we could use in the meantime and he was told no. A construction worker who was renovating the bar area overheard our plight and said that while the bar was only half built, there was a perfectly working fridge there that we could use, so he saved our day in a big way.

INFUSING ON THE RUN

My husband currently infuses my son with factor so on the trip they set up on the desk in the hotel room. We bought disinfectant to clean the desk surface and had our usual local anaesthetic cream, tourniquet, spare alcohol wipes, needles, cotton wool balls and band aids on hand. We did a lot of walking on the trip, some days 2 or 3 hours and other days up to 6 hours, not to mention being thrown around a bit on roller coasters and white water rapids rides! So it was great to know that our son had factor on board when we went off on our daily adventures.

We travelled to a developed country, so it may be different for travellers to a developing country. But in our experience, our son's haemophilia didn't impact on us visiting any of the places we wanted to visit or doing any of the activities we wanted to do. For those of you thinking of travelling overseas with a child with haemophilia, I encourage you to go for it. It might mean a bit of extra planning and thinking on your feet while you're there, but hey that's something we in the bleeding disorders community are all used to!

Glen, Jan, and their daughters are members of the Australian bleeding disorders community

WHEN YOUR DAUGHTERS BLEED TOO – A PARENTS' STORY OF HAEMOPHILIA

Glen and Jan, parents of two daughters who carry the gene causing haemophilia and have bleeding symptoms, talked to Suzanne O'Callaghan at HFA

Glen had always known there was haemophilia in his family. He himself has haemophilia, and he was aware of at least two uncles who also had haemophilia – one was a policeman and died of bleeding after being shot in a raid in the 1940s. There were 14 children in his mother's family, and 6 died young of causes that were never explained.

But it was not until his two daughters showed signs of bleeding problems that he started to join the dots on bleeding and haemophilia among women in his family.

"People didn't talk about these things then – and we didn't have the tests that we have now," commented Glen. "When I was about 13 or 14 we presume my mother had a hysterectomy or curette – nothing was explained. She went to hospital to have the operation and had so many bleeding problems that it was 6 weeks before she came out."

There were other indications of bleeding problems – bleeding for 6 weeks after teeth extractions, massive bruising and swelling when she broke her arm.

FACTOR LEVEL TESTING

Glen was part of the first generation to receive clotting factor concentrate rather than whole blood transfusions and always liaised with the Haemophilia Centre to manage any bleeding issues that might occur during surgery. So it seemed a natural course of action that his daughter should be tested before she had a tonsillectomy when she was a small child. But the results changed his understanding of haemophilia completely.

"It was a pretty big shock," he said. "We went to see the doctor at my Haemophilia Centre before we had children and understood there was a possibility our daughters could be carriers, but it was thought they definitely would not be 'bleeders'."

At 3 years of age, their daughter Sharron had factor VIII levels of 17% - in the range for mild haemophilia. The haematologists were not happy with the result and decided that her tonsils should not be removed.

Her sister was tested later at about age 3 and was also found to have low factor VIII levels like Sharron.

GROWING UP WITH BLEEDING

Growing up as a female with bleeding problems had its share of difficulties in an age when it was a commonly held belief that boys had haemophilia and girls could carry the gene, but wouldn't have bleeding problems.

Bruising could be a big issue. Jan described a single occasion when she tapped her daughter as a toddler ("she was angelic normally!"), and the bruising that resulted was so terrible that it looked like she had smacked her very hard. Alarmed, she rang a friend who was a nurse – not wanting to visit a doctor in case the doctor thought she had been abusing her daughter. Even then her friend told her not to worry, as "she couldn't possibly have haemophilia". The bruising remained a mystery until her daughter's factor levels were tested.

With their low factor levels, their mother also realised that menstruation could be a concern for her daughters and that she would need to monitor this. "I needed to talk to them about how their periods were going. I was worried that they might bleed to death!" said Jan. With a teenager's natural reserve about anything to do with their bodies, this could sometimes be an awkward conversation – preferably avoided, from at least one daughter's point of view.

MANAGING SCHOOL

However, for both parents, the hardest challenge was the attitudes their girls encountered at school.

"People would not accept that the girls had bleeding from haemophilia," said Glen.

At the beginning of every year Jan would go to the school and brief the girls' teachers and have to manage their disbelief – a painful experience. It was compounded by the bullying their daughters had to endure. Doctors' children would tell the others in the class it was not possible for them to have symptoms of haemophilia.

In the mid-1980s HIV swamped the media and the girls found themselves in the middle of the fear and discrimination that occurred during the Grim Reaper campaign. In haemophilia, HIV was a hit and miss lottery. Both daughters were lucky enough to escape infection through clotting factor products, but

The girls have each had their own approach to life, but independence and resilience has been a strong feature of both.

other young people they knew were not so fortunate. At school the talk among some students was that the girls had AIDS. This time teachers were proactive – even challenging the students in the class to find out their own HIV status – and the whole issue settled down quickly… but it was hard to forget.

INDEPENDENCE AND RESILIENCE

The girls have each had their own approach to life, but independence and resilience has been a strong feature of both. Working with horses was a big part of their family life – and fitness and exercise. Their parents encouraged them to ride horses. One in particular was very keen on riding, and her father made sure her horses were reliable and that she took care of her legs. Persuading them to take haemophilia into account with playing other sports was more of a challenge for their parents, with one daughter prepared to stop playing sports that were problematic, while the other preferred to go ahead and just take the bruises and sore patches as "an everyday thing". At school they had always wanted to sort out the bullying themselves, and their parents are uneasily aware that there were other episodes they were never told about.

As adults, the lessons and confidence Glen and Jan's daughters learned from dealing with the bullying at school stand them in good stead when they need to speak up for themselves or for each other. Their parents have watched their growth and are proud of their daughters' ability to support each other and make things happen - for example, when one was struggling with a bleeding complication at a hospital, the other advocated for her until she was transferred to the Haemophilia Centre.

AS PARENTS?

And what they have learned as parents of daughters with a bleeding disorder?

Glen explained that seeing your children's pain can be difficult. "It can be pretty hard as a dad, but it's something you just have to bear. It's something that is not going away, so you have to go through it, and do what you can for your children."

For Jan, connecting with her local haemophilia foundation and finding someone who is in a similar situation was critical. "It's such a relief to meet someone who understands!" she said.

But for both it has been hugely satisfying to see the current education materials noting that some females who carry the gene causing haemophilia can have bleeding symptoms, and that if females have factor levels in the range for mild haemophilia, they can be described as having mild haemophilia. After living through years of denial from the wider community, they now have something to show others that their daughters' experience is real – "it's there in black and white!"

HAEMOPHILIA IN FAMILIES

- Haemophilia is caused by an alteration in the gene making factor VIII (8) or IX (9)
- Men and women can carry the genetic alteration causing haemophilia and pass it on to their children
- Many women who carry the gene do not have bleeding symptoms
- Some women who carry the gene can have a bleeding tendency
- Symptoms in women include bruising easily, heavy or long menstrual periods, bleeding for a long time after childbirth, surgery, medical procedures, dental extractions, injuries or accidents
- If a female's factor levels fall in the range for mild haemophilia (5-40% of normal clotting factor), she may also be referred to as having "mild haemophilia".
- In very rare cases, some girls or women have particularly low factor levels causing them to have moderate or severe haemophilia, and they may also have joint or muscle bleeds.

For more information, visit the HFA web site – www.haemophilia.org.au

Riding horses was a big part of family life

Penny McCarthy is Haemophilia Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

GUM BLEEDING

Penny McCarthy

Gum bleeding in the absence of trauma or injury in adults with haemophilia is often reported. This can be distressing for the patient and often leads to days off work.

In managing your haemophilia it is important to use simple preventative health measures such as brushing your teeth to maintain good oral hygiene as this will prevent gum bleeding.

Without good oral hygiene gum bleeding will occur with or without haemophilia.

It is important to remember haemophilia does not cause gum bleeding.

In the absence of trauma or injury, gum bleeding is usually caused by plaque build-up. Plaque is a sticky bacterial film found on teeth. The bacteria found in plaque changes sugars into acids which then causes tooth decay.

The plaque can build up on the gum line and cause the gums to become inflamed. Inflamed gums bleed easily. The plaque if left untreated may destroy the gingival fibres that hold the teeth in place leading to periodontal disease and eventually loss of teeth.

No matter how much factor is administered, if the plaque is not removed, the bleeding will continue.

The best way to remove plaque is regular (twice a day) brushing with a fluoride tooth paste and using dental floss between the teeth plus regular trips to the dentist for professional cleaning. Rinsing will not remove plaque.

Fluoridated drinking water and toothpastes have reduced the amount of dental decay in Australia. However, remember bottled water usually does not contain fluoride! So, save your money and, if you can, drink water from the tap.

In 2010 the Australian Haemophilia Centre Directors' Organisation (ACDHO) wrote a consensus statement on the dental treatment of patients with inherited bleeding disorders. Their view is:

Without good oral hygiene gum bleeding will occur with or without haemophilia.

> *With children routine normal or assisted exfoliation of primary teeth does not require haemostatic cover. Persistent oozing and bleeding following the procedure should initially be managed with local measures, such as pressure and 5% tranexamic acid solution.*

What this means is, a person with a bleeding disorder needs to visit their local dentist for routine care. If there is bleeding following the visit to the dentist this is best managed using tranexamic mouthwash.

Tranexamic mouthwash and tablets are relatively inexpensive compared to the very costly factor concentrate, but more importantly it is more effective at stopping gum bleeding.

So next time you have bleeding gums, before you treat with factor, call your Haemophilia Treatment Centre. Try tranexamic acid and visit your dentist!

MORE INFORMATION

Australian Haemophilia Centre Directors' Organisation. A consensus statement on the dental treatment of patients with inherited bleeding disorders. Melbourne: AHCDO, 2010. www.ahcdo.org.au

Better Health Channel > Dental care - www.betterhealth.vic.gov.au

Marg Ross is the AHCDO Project Officer
Ann Wilson is the ABDR Project Officer

AHCDO UPDATE

Marg Ross and Ann Wilson

Over the last 12 months there have been a few developments at the Australian Haemophilia Centre Directors' Organisation (AHCDO).

NEW STAFF

Megan Sarson, the long-time project officer for AHCDO, has taken a two year leave of absence to go and live and work in Ethiopia with her husband and daughter. This is not the first visit for Megan and family to Ethiopia and they are looking forward to settling into the community and reestablishing contacts again. Megan will be missed; however, she will be replaced in her role by Marg Ross who joined AHCDO in January 2015.

Marg worked previously in the Faculty of Science at the University of Melbourne for several years. As Business Manager in the School of Chemistry, she supported Professor Frances Separovic, the Head of School, with the School's research and educational programs. The School of Chemistry is one of Australia's leading research centres in the chemical sciences and has strong links to the community through various programs, collections and public events. Marg has also held Senior Project Officer roles in the Faculty of Science Secretariat.

Marg is looking forward to working with HFA over the next couple of years.

Ann Wilson joined AHCDO as the ABDR Project Officer in March 2014. Ann has over 20 years research experience in a number of science and public health fields, including developing diagnostics, working with genetic databases, creating online surveys for young people seeking help and evaluating ways of improving clinical practice. Ann has also been involved in education through teaching not just science, but also research methods and improving nursing practice through understanding different cultures and patient needs.

Ann's role at AHCDO is to analyse and present the data collected in the Australian Bleeding Disorders Registry (ABDR) through means such as reports and publications. At present she is responsible for ensuring that ethics approval for the collection and use of the ABDR data is current nationwide.

The AHCDO team. Back: Marg Ross; front: Ann Wilson

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

Peter O'Halloran is Executive Director and Chief Information Officer at the National Blood Authority

ABDR AND MYABDR CONSENT TO PRIVACY

Suzanne O'Callaghan and Peter O'Halloran

WHAT'S NEW?

From 26 January 2015 patients at Haemophilia Treatment Centres (HTCs) are being asked to complete a new ABDR (Australian Bleeding Disorders Registry) privacy consent form.

If you use MyABDR, you will have been asked to complete the new ABDR privacy consent form when you logged in on or after 26 January 2015. You need to complete the consent form before you can continue.

Alternatively, your HTC may ask you to complete a printed consent form.

This is a progressive transition process for the ABDR. This means that HTCs will work through their list of patients over time to document their consent for the ABDR. So if you are a patient at an HTC and already have your data in the ABDR, your HTC will still keep collecting your data in the ABDR until you complete the consent form.

WHAT IS THIS ALL ABOUT?

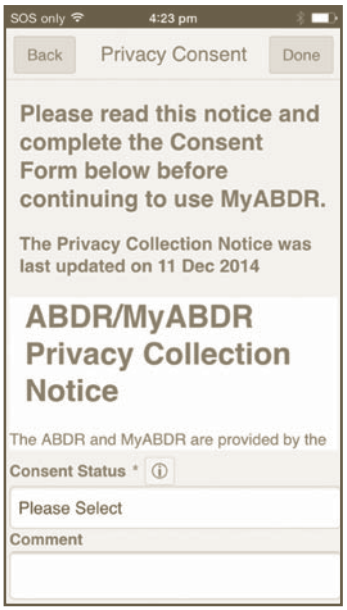
The Commonwealth Privacy Act - an Australian law that regulates how your personal information is handled - has been strengthened. As a result, you are now being asked formally if you consent or agree to have your personal information in the ABDR.

You may also be asked to consent on behalf of your child if they are the patient at the HTC and are under 18.

This is called an **opt-in** system. It will make it clear whether you have agreed to have your personal information in the ABDR. You also have the opportunity to find out more about the ABDR and how your personal information is used and protected

In the past it was an **opt-out** system – your personal information was kept in the ABDR unless you asked for it not to be entered in the system. You may recall your Haemophilia Treatment Centre talking to you about the ABDR and giving you a pamphlet.

"Our patients' data in the ABDR has not changed – all that we are doing is confirming their consent to have their personal information included. This is an important process to keep up-to-date with national privacy law. It will mean we will have clear patient consent to collect information to improve individuals' clinical care and to assist with better planning for improvements in



product availability. AHCDO is also working on a parallel process to obtain a broad approval from hospital ethics committees to enable this data to be used for research to improve care," said Dr John Rowell, Director of the Queensland Haemophilia Centre and ABDR Co-ordinator with the Australian Haemophilia Centre Directors' Organisation (AHCDO).

WHAT IS THE ABDR?

The Australian Bleeding Disorders Registry (ABDR) is a computer database of health care information about people with bleeding disorders. The ABDR is the system used by Haemophilia Treatment Centres around Australia for the clinical care of their patients.

FOR MORE INFORMATION

Visit the ABDR MyABDR Privacy Consent page at **www.haemophilia.org.au/myabdr.**

Or collect the ***Consent to Privacy*** leaflet from your Haemophilia Centre.

Or ask HFA to send you a ***Consent to Privacy*** leaflet – email hfaust@haemophilia.org.au or phone 1800 807 173 toll free.

NEED HELP?

Contact the MyABDR Support Team
Available 24hrs, 7 days a week
T: 13 000 BLOOD (13 000 25663)
E: myabdr@blood.gov.au

HEP C NEWS

Addressing the impact of hepatitis C on the bleeding disorders community is a priority for HFA. In the last few months hepatitis C has taken a high profile on the national government agenda as well.

HEP C INQUIRY

In December 2014 the Australian Government House of Representatives Standing Committee on Health commenced an inquiry into hepatitis C in Australia.

What is the inquiry investigating?
The Inquiry is looking at particular issues, including:

- How common hepatitis C is in Australia
- The costs associated with treating the short term and long term impacts of hepatitis C
- Methods to improve prevention of new hepatitis C infections

And methods to reduce the stigma with a positive diagnosis through:

- The public health system
- Public health awareness and prevention campaigns
- Non-government organisation health awareness and prevention programs.

Public hearings
The Australian Government heard witnesses on hep C, including HFA, at the recent Public Inquiry Hearings.

Public Hearings for the Inquiry took place in January 2015. HFA had the opportunity to present evidence at the Melbourne Hearing on 21 January 2015 and Gavin Finkelstein, HFA President, told his personal story of living with hepatitis C. You can read the transcripts of the Hearings at www.tinyurl.com/inquiryhearings.

The Inquiry is continuing to gather evidence and HFA made a written submission to the Inquiry on the issues for the bleeding disorders community in February 2015. Some community members also made individual submissions.

We hope this Inquiry will be a catalyst for real and positive change for Australians with hepatitis C, and particularly people with bleeding disorders – and their partners, families and carers, who are very much affected by it.

For more information on the Inquiry, go to www.aph.gov.au/hepatitisC.

PBAC – NEW TREATMENTS

In March 2015 the Pharmaceutical Benefits Advisory Committee (PBAC) will be meeting to consider whether to recommend adding several new hepatitis C treatments to the Pharmaceutical Benefits Scheme (PBS):

- **Asunaprevir** (Sunvepra®) - for the treatment of chronic hepatitis C genotype 1b
- **Daclatasvir** (Daklinza®) - for the treatment of chronic hepatitis C
- **Ledipasvir with sofosbuvir** (Harvoni®) - for the treatment of chronic hepatitis C genotype 1 in adults
- **Ribavirin** (Ibavyr®) - for the treatment of chronic hepatitis C (genotype 2 or 3) in combination with sofosbuvir in patients 18 years or older who have compensated liver disease
- **Sofosbuvir** (Sovaldi®) - for the treatment of hepatitis C viral infection

Listing these new treatments on the PBS would provide equitable and affordable access to Australians.

You may recall that sofosbuvir went before PBAC in July 2014 but was rejected on the basis of its high cost and limited information about cost-effectiveness. It is now being resubmitted with more information.

These new treatments have been described as "game changers". They are part of the new wave of Direct Acting Antiviral (DAA) drugs that are far more effective against hepatitis C than the previous treatments. Most of these treatments are already available in other countries.

In clinical trials they have had very high success rates – over 90% for some – with few side-effects, and shorter treatment courses. Some need to be taken in combination with other medications (eg, interferon, ribavirin, ledipasvir) to be effective. Some will be available in interferon or ribavirin-free combinations. Some have had encouraging results even with people who previously had unsuccessful treatment or who have advanced liver disease. Ledipasvir with sofosbuvir was trialled in a small study of people with bleeding

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disorders and hepatitis C genotype 1 in New Zealand, with excellent success rates, few side-effects and no safety concerns[1].

HFA provided community comments to PBAC about these treatments in February 2015.

HFA HEP C SURVEY

You may have seen the HFA hepatitis C survey earlier this year. This was an important way for HFA to gather the personal stories of community members affected by hepatitis C to submit as evidence for the HFA PBAC comments and for the Public hearing and submission to the Inquiry.

Thanks to anyone who completed the HFA hep C survey. Your words were very powerful and they were extremely valuable for our evidence!

WHAT HAPPENS NOW?

Advancing liver disease and limited treatment options is a critical problem for some of our community members with hepatitis C. Treatment to cure their hepatitis C is crucial – and urgently required.

HFA is pursuing every avenue possible around access to these new treatments for affected community members.

In November 2014 we sought expert advice from the Australian Haemophilia Centre Directors' Organisation and from hepatitis specialists to clarify the current situation for affected people with bleeding disorders nationally – their need for treatment, potential benefits and issues relating to current and upcoming treatments. Collaborative work on this is ongoing.

HFA has provided written and oral submissions to government on these new treatments and will be following up with more representation to government.

AND IF YOU HAVE HEP C?

If you have hepatitis C and a bleeding disorder, remember that you would need to have your liver health assessed before you could be considered for treatment:

- Make sure you have your liver health checked regularly
- Stay in touch with your hepatitis clinic about what's new
- And don't forget to go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable at the moment.

REFERENCES

1 Kulkarni, R, Mauser-Bunschoten, EP, Stedman, C, Street, A. Medical co-morbidities and practice. Haemophilia 2014;20(Suppl. 4):130-136.

NEW STAFF

Philippa Bagnall joined the HFA team as Fundraising Co-ordinator in January 2015.

This is a busy role, with responsibility for managing the HFA fundraising and member database and assisting Natashia and the team at HFA with their fundraising activities.

Philippa brings valuable experience to the role, not only in fundraising, but also in health promotion and awareness. Previously she held the position of Fundraising Manager for SIDS and Kids NSW, and was responsible for running all their fundraising activities, including Red Nose Day.

"Events such as these are essential in not only providing vital funding resources, but also allow for greater awareness, education and understanding throughout the community," said Philippa. She is looking forward to being part of HFA's awareness raising activities, including Haemophilia Awareness Week and Red Cake Day.

Outside of work, Philippa has a very active life, and enjoys walking, reading and swimming. "But at the moment, most of my spare time is taken up with raising a 7 year old daughter and training a Labrador puppy," she commented.

Her new role at HFA is a welcome way to work in a sector she loves.

"It's a great opportunity, and I am enjoying learning more about the bleeding disorders community and using my experience at HFA."

HFSA UPDATE

SA Physio to attend 14th International MSK Congress

Cameron Cramey is the senior physiotherapist at the Royal Adelaide Hospital in Adelaide, South Australia, who works with people with bleeding disorders. Cameron is also the newly elected Chairman of the Australian New Zealand Physiotherapy Haemophilia Group which is a national group auspiced by Haemophilia Foundation Australia (HFA) to support clinical excellence in haemophilia physiotherapy.

Cameron has been selected by Haemophilia Foundation Australia (HFA) to attend the 14th World Federation of Hemophilia MSK Congress which will be held in Belfast Northern Ireland in May 2015. The Congress is a three day event which focuses on the impact of bleeding on the musculoskeletal system and is often attended by orthopaedic specialists and physiotherapists.

TEAM.FACTOR

The Bupa Challenge Tour 2015

On Friday 23 January 2014, Team.Factor headed by Dr Simon McRae participated in the Bupa Challenge Tour to raise funds for Haemophilia Foundation Australia.

The Tour started in Glenelg and finished in Mount Barker in South Australia – that is over 150 km! Dr Simon McRae, Andrew Atkins, Dr Uwe Hahn, Dan Drake, Phil Shaw, Cameron Cramey, Joanna McCosker and Dr Tina Noutsos all took part in the challenge, and what a great effort in all finishing the race.

THE RIDE

The Bupa Challenge Ride is part of the Santos Tour Down Under in Adelaide, the first stop on the world elite cycling calendar. It gives regular cyclists the opportunity to ride the same Stage 4 route on the same day as the elite cyclists in the Tour Down Under. The tour farewelled Cadel Evans, the Australian cycling champion, who announced that the 2015 Tour Downunder will be his final Union Cycliste Internationale World Tour event before he retires.

Andrew Atkins said, "it was a perfect day for riding, cool with no breeze. A long but scenic ride from the beach through to the Adelaide hills – perfect. The team enjoyed it and thanks to everyone who contributed"

THANK YOU

Thank you to Dr Simon McRae , Andrew Atkins, Dr Uwe Hahn, Dan Drake, Phil Shaw, Cameron Cramey, Joanna McCosker and Dr Tina Noutsos for participating in the race and raising money for Haemophilia Foundation Australia. Also, a thank you to those who made donations and supported the team. The team has raised $2,173.75 - what a fantastic effort!

RANDALL STEPHENS

- Cycling from Perth to Melbourne

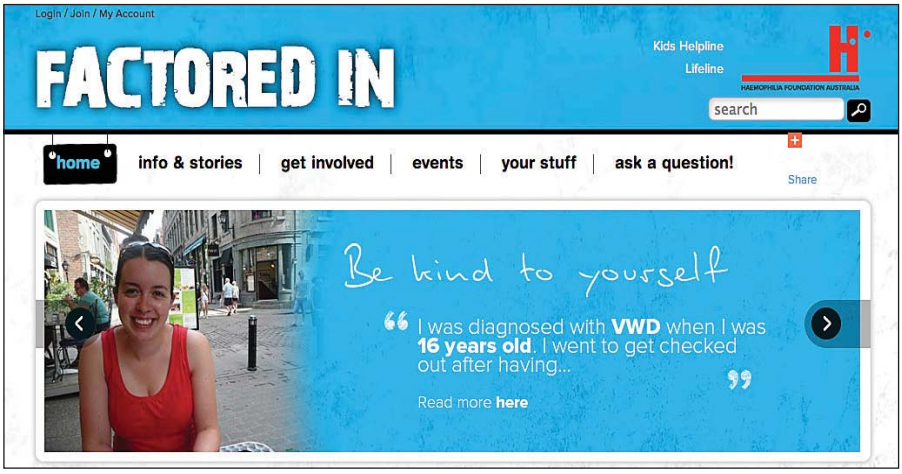
Randall Stephens departed Melbourne in August 2014 on his epic 5,000km cycling journey across Australia. Randall has haemophilia and was hoping to raise awareness and fundraise along the way for Haemophilia Foundation Victoria.

Randall has made it across from Perth to Melbourne – what a tremendous effort! To date he has raised over $4,000 for Haemophilia Foundation Victoria. We congratulate Randall on achieving his goal.

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia

YOUTH UPDATE

Hannah Opeskin



FACTORED IN MODERATION WORKSHOP

February saw the beginning of change for the Factored In website (factoredin.org.au). It started with training a small group of young people as Factored In moderators in Melbourne late February/early March 2015.

They received technical training in how to moderate comments and upload events on the website.

Training also involved discussion about the following topics:

- Establishing further possibilities of engagement with young people
- How to increase promotion among youth
- Increasing youth involvement and interaction
- Involving youth to ensure sustainability.

As part of an initiative to ensure that young people across Australia take ownership of the website, this small group of young people will contribute to the website, promote events and moderate comments.

Training topics to ready these young people included:

- Positive reinforcement
- Reputation management
- Confidentiality
- Mental health and wellbeing
- Risk management.

FACTORED IN IMPROVEMENTS

As a result of the Factored In evaluation survey last year, we have already started making some changes to the website:

- Software updates
- Simplifying the menu.

The moderation training group will also assist HFA with identifying potential improvements that could be made to the website.

The Factored In Moderation Team

Ben's excellent US adventure

In January I travelled to the USA for 10 days, travelling around the states of California, Arizona, Utah and Nevada. This trip was my first international adventure and as such I had to learn many important skills even before I left Australia. This included how to get a passport, organize notes to allow my treatment factor across international borders and finding travel insurance that would cover haemophilia related incidents.

The trip itself started peacefully; my treatment kits passing easily through customs before a 15 hour long airbus flight across the Pacific Ocean to Los Angeles. With a 12 hour stopover in Los Angeles I had some time to check out some local tourist attractions like Venice beach, Santa Monica Pier and the California Science Centre before catching another flight into Phoenix, Arizona at 2am in the morning.

NACCHO CONFERENCE

The next few days after that were spent at the NACCHO conference (North American Camping Conference of Hemophilia Organizations) where I got to meet some amazing people from Turkey, Canada, The Netherlands and of course the US who all ran camps for kids with haemophilia. These few days were an amazing learning experience and it was truly inspiring to be around some of these brilliant people and learn how and why they do what they do; I have great hopes of one day getting to visit one of their camps myself.

HIKING THROUGH UTAH

After the conference was over, the final portion of my adventure was spent travelling through southern Utah through some absolutely stunning national parks including the Grand Canyon National Park, Antelope Canyon and Zion National Park. This would have had to be my favourite part of my trip; with my camera over one shoulder and my little Esky of emergency factor over the other: hiking through these great American national parks through landscapes I had seen countless times on a screen but had never been able to truly experience until now.

LAS VEGAS AND HOLLYWOOD

My last night in the US was a late one, walking down the Las Vegas strip and looking into some of the famous casinos (though being just under 21 years of age the option of gambling was totally unavailable), the lights of which could be seem filling the horizon from over 2 miles away. After flying out of Vegas back into LA most of my final 12 hours before my flight back home was spent at the Universal Studios theme park, the highlight of this being the famous Universal Studios tram tour where we went through sets of a lot of famous movies and TV shows including Desperate Housewives, Psycho and War of the Worlds.

COMING HOME

Totally exhausted after far too many hours of being awake I fell asleep during the take-off from my flight to wake 11 hours later only 4 hours away from home.

The end of my adventure was really quite easy; I had no trouble getting through customs and my family was there waiting for me to take me home where I was more than keen to get some more sleep and spend the next few days fighting the jetlag.

For those of you out there with haemophilia thinking that maybe you want to travel the world, I would definitely recommend it; I have well and truly caught the travel bug and can't wait for my next chance to go out and see the world. The prospect may be scary for now but if you prepare well and travel with friends you trust then I can almost guarantee you will not regret it.

Ben Inglis

CALENDAR

World Haemophilia Day
17 April 2015
www.wfh.org/whd

Red Run Classic
Sunday 17 May 2015
New Farm Park, Brisbane
www.haemophilia.org.au/rrc

17th Australian & New Zealand Conference on haemophilia & related bleeding disorders
1-3 October 2015
Gold Coast
Tel 03 9885 7800
Fax 03 9885 1800
Email hfaust@haemophilia.org.au
www.haemophilia.org.au

Haemophilia Awareness Week
11-17 October 2015
Tel 03 9885 7800
Fax 03 9885 1800
Email hfaust@haemophilia.org.au
www.haemophilia.org.au

CORPORATE PARTNERS

Haemophilia Foundation Australia (HFA) values the individuals, philanthropic trusts and corporations which have made donations to education activities and peer support programs and Corporate Partners that sponsor programs to enable HFA to meet its objectives of:

- advocacy and representation that improves access to treatment and care for people with bleeding disorders
- education and peer support activities that increase independence and the quality of lives of people with bleeding disorders, and their families
- encouraging clinical excellence in haemophilia care, and promoting research.

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Sunday 17 May 2015
5km and 10km route
Meet and finish at New Farm
Registration from 6.30am
Race begins at 8am.

The Red Run Classic is a fundraising run/walk for Haemophilia Foundation Australia and Haemophilia Foundation Queensland. Funds raised will provide programs and services for the bleeding disorders community across the nation. Join hundreds of other women, men, teenagers, children and families to have fun while raising money for a good cause. If you are a serious competitor make the Red Run Classic one of your big events, or walk with your family and friends for a fun social morning. All entrants will receive a free RRC commemorative T-shirt.

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