

National



Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

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WORLD CONGRESS THE COUNTDOWN IS ON!



**WFH 2014
WORLD
CONGRESS**

Melbourne, Australia • May 11-15



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6 REASONS TO ATTEND WFH 2014 WORLD CONGRESS IN MELBOURNE, AUSTRALIA

1 PARTICIPATE IN THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

and network with people around the world.

2 GAIN KNOWLEDGE

of cutting-edge scientific research and clinical trials, profiling future advances in treatment and best practice care

3 SHARE INSIGHTS

on holistic patient healthcare issues and multidisciplinary care.

4 EXCHANGE WITH HEALTHCARE PROFESSIONALS AND PATIENTS

on challenges and solutions to improve treatment and care throughout the world.

5 COLLABORATE WITH LEADERS;

advance the WFH's vision for Treatment for All and lay the foundation for the next 50 years.

6 DISCOVER MELBOURNE

with your family and friends.

CONGRESS REGISTRATION

The next discounted registration closes March 14, 2014.

To register online and for information on prices refer to the Congress brochure that is enclosed in this issue of *National Haemophilia* or visit www.wfh2014congress.org.

FUNDING STILL AVAILABLE FOR CONGRESS!

If you need some financial help to get to the upcoming World Congress, please contact your local Foundation or HFA for information about the further funding that may be available to you.

We want to be sure everyone has the chance to attend the Congress and have had special fundraising campaigns so we have funds available to share around to people with bleeding disorders around Australia.

Contact scaris@haemophilia.org.au at HFA if you want more details.



Haemophilia Awareness Week
13-19 October 2013

P: 1800 807 173 W: www.haemophilia.org.au

HAEMOPHILIA AWARENESS WEEK

Haemophilia Awareness Week and Red Cake Day were held this year from 13 to 19 October 2013. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about inherited bleeding disorders.

There was great interest in the week and we had many supporters to help us fundraise and raise awareness over the week. Red Cake Day was a hit again this year, and proved to be a versatile concept for individuals and organisations along with schools and companies that wanted to do something practical while highlighting the needs of people with bleeding disorders.

Over 100 schools, hospitals, libraries, families and local communities around the country received promotional materials to help them run their own Red Cake Days and Haemophilia Awareness Week activities. They held different types of events, but they all worked together with us to raise awareness about bleeding disorders or host a Red Cake Day. We are grateful for the support and uptake of this exciting event which we hope is becoming a regular feature on everyone's calendar.

Many of our corporate supporters including Baxter, Bayer, Biogen Idec and CSL Behring held a Red Cake Day at their offices and raised awareness of the needs of people with bleeding disorders with their colleagues, many of whom work in other areas of their businesses.

An exciting Red Cake Day event at Federation Square in Melbourne was sponsored by Pfizer. The rainy day did not dampen the enthusiasm of the people who came to see Maria Vella from the Great Australian Bake Off demonstrating her cake decorating skills. We are grateful to the Cupcake Bakery for donating cupcakes which were sold in support of Red Cake Day.



Above left and above right: Red Cake Day in Federation Square

Below right: Paint the Town Red, Neerim South

PAINT THE TOWN RED, NEERIM SOUTH & BENDIGO BANK BRANCHES, SOUTH GIPPSLAND REGION

Now in its fifth year, the township of Neerim South in Victoria once again hosted 'Paint the town Red'. The event is organised by Donna Field and a wonderful team at the Neerim District Community Bank®. We are grateful that staff at Bendigo Bank Branches in the South Gippsland Region also displayed posters and promotional items to raise awareness about bleeding disorders and helped to raise funds. *Paint the Town Red* and fundraising from the Neerim District Community Bank® and Bendigo Bank Branches South Gippsland Region raised \$1,980 for Haemophilia Foundation activities.

THANK YOU NEWSLETTER

A newsletter highlighting all the events held during Haemophilia Awareness Week will be distributed to participants soon and will be available on the HFA web site. If you wish to receive a copy please email Natasha at ncoco@haemophilia.org.au

Thank you to everyone who participated in Haemophilia Awareness Week and Red Cake Day activities! 🍪

HAEMOPHILIA AWARENESS WEEK



Grainne Dunne is the Clinical Nurse Consultant Haemophilia at the Sydney Children's Hospital, Randwick. Robyn Shoemark is the Clinical Nurse Consultant Haemophilia at The Children's Hospital at Westmead.

AWARENESS RAISING AT THE SYDNEY CHILDREN'S HOSPITAL NETWORK

Grainne Dunne and Robyn Shoemark

The Sydney Children's Hospital Network consists of two large children's hospitals, located approximately 35 km apart in Sydney. Together both hospitals serve the children of NSW, ACT and sometimes beyond this area.

During national Haemophilia Awareness Week both hospitals celebrated awareness about haemophilia and bleeding disorders in similar yet different ways.

SYDNEY CHILDREN'S HOSPITAL (SCH), RANDWICK

Preparation for the week was led mainly by the haematology day ward Clinical Nurse Specialist Brigitte Montzka and Clinical Nurse Educator Kim Traish with guidance from their haemophilia Clinical Nurse Consultant.

The aim of the week was to educate staff and visitors about bleeding disorders. Haemophilia and other bleeding disorders are rare, so this was an ideal opportunity to increase the profile of bleeding disorders. For weeks prior, staff prepared educational decorations for the ward (fun blood droplet cut outs with bleeding disorder questions and answers on them); informative posters about haemophilia; 'fun' fundraising was arranged, e.g. count the red lollies in the jar competition, red cake sales; colouring in competition for the children which showed off some great budding artists!!

On Thursday, we held 'Red Cake Day' where all staff dressed in red, sold their greatly baked red cakes and other yummy treats. Then during meal breaks, everyone grazed in the tea room until no more party food could possibly be had!! Altogether \$166 was raised and donated to Haemophilia Foundation NSW.

Bleeding disorder in-services for the staff were arranged for each day. Speakers consisted of Clinical Nurse Specialists from the



Above: Staff enjoying 'haemophilia quiz time' on Red Cake Day at SCH

haematology ward, the Clinical Nurse Consultant for haemophilia, the NSW Haemophilia Foundation President and pharmaceutical representatives. The in-service week ended with a mind blowing haemophilia quiz where the haematology day ward competed against the haematology overnight ward! There was lots of positive energy flowing and great team spirit in making Haemophilia Awareness Week a fun yet very productive week for haemophilia awareness and learning.

THE CHILDREN'S HOSPITAL AT WESTMEAD (CHW)

Haemophilia Awareness Week kicked off on Monday 14 October with an information stand located in the

hospital foyer. The stand was refilled with leaflets and balloons each day as people passing had depleted stocks from the previous day. The information was getting out there as leaflets and colouring in flyers were taken with enthusiasm.

On the Wednesday, for Red Cake Day, Haematology doctors and nurses baked red velvet cupcakes and sold them to staff to raise awareness and funds for HFNSW. A total of \$246 was donated. Well done bakers. On the Thursday, hospital staff organised a fun filled day with competitions for children and lots of balloons. ■

FROM THE PRESIDENT



Gavin Finkelstein

WORLD CONGRESS

It has been a busy quarter for Haemophilia Foundation Australia (HFA) for several reasons. Of course the 2014 World Congress is getting closer by the day and our work is ramping up. Sharon Caris, Natashia Coco and others at the HFA office are working closely with World Federation of Hemophilia (WFH) staff to make sure the Melbourne Congress experience will be a great one for everyone.

I can't urge readers more strongly about registering from Congress. The Congress is unique. It is truly a celebration of what the worldwide bleeding disorders community has achieved as well as a flag for the important work still to be done to achieve the WFH vision, **Treatment for All**. There are so many elements to the Congress. Foremost it is the forum for hearing cutting edge information about treatment and care. It is really important for Australians with bleeding disorders to know as much about their bleeding disorder as possible so they can take care of themselves in the best way. The Congress is great for that – you can find out so many new things on so many topics from issues about treating bleeding and looking after your joints to new joint surgery options and new treatments for blood borne viruses. The program offers interesting material for older people like me, as well as for families who are new to bleeding disorders and are wondering that the future holds for their children. For health professionals the meeting provides a great chance to network with global peers and to learn more about best practice treatment and care. The Congress program is rich with contributions from Australians as well as those from other parts of the world who are

sharing their experiences and ideas.

Perhaps one of the most exciting aspects of every WFH World Congress is that they are attended by people from many different countries - we look forward to meeting the representatives of the 122 National Member Organisations (NMOs) likely to come to Australia for the Congress and the General Assembly of WFH that follows. Congress is a wonderful way to see and hear more about the work of the many WFH volunteers and staff who work with NMOs to improve access to treatment and care in countries where there is still little access to health services and clotting factor treatments.

The WFH vision, **Treatment for All**, is indeed making a difference around the world but there is still a long way to go. With 75% of the world's bleeding disorders population as yet undiagnosed or untreated, the vision is critical. If you attend the Congress you will hear more about this and of some the innovative advocacy programs and coalitions of diverse stakeholders that are making a difference. One of the things I find incredibly motivating is how we can learn from the experiences of others with bleeding disorders and their carers and treaters regardless of where we live.

I can honestly promise that you will not be disappointed if you attend the 2014 World Congress in Melbourne. There is something for everyone, and your understanding of the personal and organisational bleeding disorders community challenges will broaden and deepen I have no doubt. If you are involved in a State/Territory Haemophilia Foundation because you want to improve care and programs in your area you will come away with new ideas for your own Foundation. Or if you are interested in learning

more about emerging treatments for yourself or a family member, or gene therapy for example, you will definitely have a chance to find out more. It is no cliché when I say the Congress has something for everyone – it really does!

As you would guess, a successful Congress needs a well-oiled machine to run it! And the WFH Congress Secretariat is very much that. If you have any questions during the registration or hotel bookings process, WFH is just an email away. In the meantime HFA is working closely with WFH to make sure they know all the local quirks and services of Melbourne so that the Congress experience is a good one for all visitors. Our work involves sourcing suppliers, planning the cultural and social program, volunteer recruitment and training, providing support and information to overseas visitors, and helping to set up the treatment room which will be used by overseas visitors. If you have any queries, please do not hesitate to contact HFA – hfaust@haemophilia.org.au.

As many readers know, HFA put out a call to people who would like some funding assistance to attend the Congress. I am pleased to advise that we offered funding to 35 people from all Australia before early bird registration closed. This is in addition to the funding offered by local Foundations. We are now working with each Foundation to find the best way to provide further incentives and financial assistance to make sure others who want to get to Congress can do so. We have had a special fundraising program to raise funds for this purpose, so if you know of anyone who would like to get to Congress but needs some financial help please let them know to contact HFA for more information.

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HFA COUNCIL

The HFA Council meeting was held over 26-27 October 2013 and was attended by Delegates of each of our member Foundations. We also had several observers in attendance including from South Australia, Tasmania and Queensland along with most of the HFA staff. The South Australia observer was Paul Bonner who attended Council in the absence of a formal Delegate from South Australia after HFSA wound up. I am pleased to say that HFA has remained connected with individuals with bleeding disorders and their families from South Australia, as well as with health professionals at the Haemophilia Centres in Adelaide. We sponsored three young men from South Australia to attend the Youth Leadership and Mentoring Program earlier this year and are working with them on some youth activities they are planning for later this year. The HFA Board has made a special decision to proactively encourage South Australians with bleeding disorders to attend the Congress and will provide some additional funding to allow this to occur.

The HFA Council meeting is held each year combined with our Annual General Meeting. Council is working on some significant changes to the way it works so that decision making can be quicker and more flexible. This will involve doing away with the formal regular meetings of the Executive Board and having a smaller and more agile Council. It is proposed that every member Foundation (plus observers and/or special experts as required) will be represented at the Council meetings which will be held more often during the year. We think this is important so that we can be more responsive to challenges when they arise. There is still more consultation work to be done before these proposals are put in place, but they are well under way.

MYABDR

An important part of the Council meeting was the presentation on MyABDR by Suzanne O'Callaghan, HFA Policy Research and Education Manager with Michael Linegar, Program Manager, iblood Applications Development at the National Blood Authority. Council members and staff were updated on the excellent collaboration between HFA and the NBA to develop an app for people with bleeding disorders to record information about their bleeds and their home treatment. This can be used by patients and their health professionals to monitor and improve their care. MyABDR includes specific security features to protect privacy and details of these are available in the regular updates provided in our newsletters and on the HFA website.

TREATMENT SUPPLY PLANNING

It was also a pleasure to welcome Mr Leigh McJames, General Manager of the National Blood Authority (NBA) who attended with Michael Stone, Deputy General Manager and General Counsel of the NBA to address Council. Leigh was able to provide an overview of the role of the NBA to purchase and supply blood and blood products on behalf of Australian governments.

The NBA has provided certainty around supply planning since it was established in 2003; however, it is not without significant challenges with escalating costs and the various complexities of purchasing and supplying blood and blood products to all Australians. Leigh identified some of these and some of the objectives of government procurement processes including the need to meet clinical and patient needs as well as achieving the best value for the money spent by governments for these treatment products.

Since the Council meeting, the NBA has called for tenders for the supply

of recombinant factor VIII (rFVIII) and recombinant factor IX (rFIX) from 1 July 2014 because the current contracts for the supply of these clotting factors will expire on 30 June 2014. HFA was looking forward to the potential for these tenders to result in a broader suite of products being available to our members, including the potential for long acting rFVIII and rFIX products that are likely to come to the global market in the next year. HFA is of the view that some patients would like additional choice of recombinant factor VIII and IX products given a likely increasing range of options available, and that some would also like the opportunity to use long acting therapies when registered and available in Australia.

HFA recognises the funding challenges for governments but holds its view that a range of different products is a preferred system to enable patient and clinician choice based on clinical need and also because of the value in encouraging and supporting the development of clinical experience with a range of products. HFA has provided feedback to the NBA about the transition when the last contracts led to different treatment products being available, treatment options were reduced and of the anxiety and disruption caused to patients and Haemophilia Centres. The NBA has indicated early transition processes would be put in place if required. HFA maintains its view that the product range should be increased rather than contracted with tender processes.

Wishing you all well over the festive season and a happy and healthy New Year to all. ❧

CONGRESS EXPERIENCES

With World Congress only four months away, anticipation about this extraordinary international event is growing. What's in store for people who have registered to attend?

This is one of the few health conferences with both health professionals and community members as delegates. It gives a very different flavour to the event.

In this article, community members, haemophilia foundation representatives and health professionals reflect on their experiences and the highlights of World Congress.

TURKEY, 2008

A YOUNG PERSON'S PERSPECTIVE

As a member of the HFA Youth Committee, Robert McCabe attended the World Congresses in Istanbul and Buenos Aires.

The World Congress in Turkey was one of the most amazing experiences I have ever had in my life. I met a lot of people and gained contacts and friendships which will last a lifetime. Haemophilia became the universal language and broke down the communication barriers between the participants. I was able to meet many other young people who had a connection to the bleeding disorders community. Eventually, we were able to gather a few people together and look at the night life of Istanbul.

For me the most memorable thing about the World Congresses was hearing the stories of those who live in countries that have little to no access to safe treatment products. It really showed how much more work that there is to do. And I definitely got a lot out of meeting people from around the world. From treatment providers to people with or who are affected by a bleeding disorder, listening and

sharing stories with others shows you how similar and different we all are.

BUENOS AIRES, 2010

THE VIEW FROM THE EXHIBITION BOOTH

Maria Wensing attended the Congress at Buenos Aires as part of the HFA team promoting Melbourne as the venue for the 2014 Congress. Maria is from Canberra, has two sons with severe haemophilia A and is currently Vice President of HFACT and an Executive member of HFA Council.

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

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

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



Above: Robert and friends at the Istanbul Congress

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

THE VIEW FROM THE POSTER EXHIBITION

Suzanne O'Callaghan is HFA Policy Research and Education Manager. She had two posters accepted for the poster exhibition at the Buenos Aires Congress.

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

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The audience was made up of more than 100 different nationalities, with simultaneous translation into four languages. It was like being at the United Nations! There was a real emphasis on personal stories in the program and this seemed to create a lot of enthusiasm to share experiences and develop new friendships. This continued on for the socialising in the evening, when we caught up with others staying at the same hotel and went off to explore the city restaurants together.

There were many posters displayed at the World Congress poster exhibition. Although the presentation time at the poster exhibition was intended to give delegates a time to discuss the posters with their authors, it was also a great opportunity to talk with other poster authors. For example, Chantal Lauzon from Haemophilia Foundation New Zealand and I found ourselves grouped with a colleague from Iran and had a very lively and interesting conversation together about how to promote feedback on resources from our communities.

A PARENT'S PERSPECTIVE

Michelle Sullivan has two sons with severe haemophilia A and is Haemophilia Foundation Victoria President. Buenos Aires was her first World Congress and she focused on the presentations relating to children and parents.

There were so many people to meet, so many stories to hear and so many sessions to attend. I learned a great deal: in particular how far the management of haemophilia has come, how fortunate we are here in Australia in regard to access to treatment options, and how scientific development is working towards better treatment options (for example prolonged half life of recombinant factors, alternative routes of administration of factors, successful clinical trials underway already).

Of all the sessions I attended however, it was those where 'real people' spoke about their personal 'real' experiences – from all around the globe - that had the most impact on me.

THE PRESIDENT'S PERSPECTIVE

Gavin Finkelstein is HFA President. Hemophilia 2010 was his fourth World Congress.

The World Congress gives you perspective on where Australia stands



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

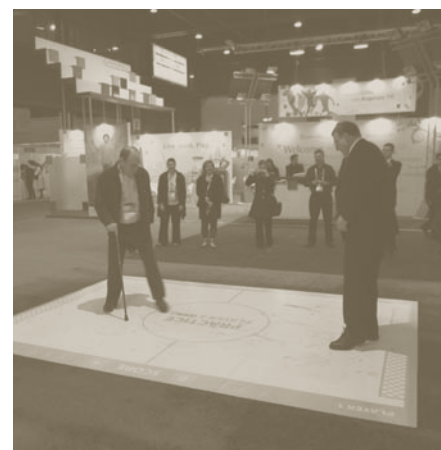
The Congress can also be very exciting – you see all the new innovations and the latest in treatment and care. And most importantly, there is always hope at the end of it.

A PERSONAL PERSPECTIVE

Zev Fishman is a member of Haemophilia Foundation Victoria. He attended the Buenos Aires Congress as part of the HFA delegation.

My name is Zev Fishman and I am a 62 year old man with severe haemophilia A. Let me tell you about what I took away from the Congress.

What I realised is how lucky I am to have been born in Australia. This was my first exposure to the world family of haemophilia. From the first day at registration I felt a belonging, a feeling that all of these 4000+ delegates had some sort of connection to this bleeding disorder. I was full of excitement; I didn't want to know



Buenos Aires, 2010

Above left: Maria Wensing and Michelle Sullivan exploring the trade exhibition

Above right: Suzanne O'Callaghan beside her poster

Middle: Gavin Finkelstein and the Thai Twinning delegation with the shared HFA/Thai Twinning poster

Below: Zev Fishman and Gavin Finkelstein try out the infrared football game at the World Congress

about the cure or the world's best practice for orthopaedic surgery. I needed to talk to people with haemophilia; I needed to know their story. I wanted to stop that bloke who walked just like me. I wanted to tell him that I understand what he has been through and talk to him about the treatment that he uses and the surgical procedures he has had.

Well, it wasn't like that. One of the first facts I learned at the very first Plenary was that only 30% of all people with haemophilia have treatment or are diagnosed. I couldn't believe it was true - that 70% of all people who have haemophilia struggle with issues that I did before the 1960s: when will this bleed stop? When will the pain go away? Why can't I do things that everyone else can?

As hard as it was to deal with the thought that so many don't have treatment and resources, I was heartened by what is being done by so many to turn things around. I realised that one reason WFH puts on a Congress every two years is to raise funds to develop programs that help communities with no or little access to treatment.

It was a privilege to be part of the Congress. We should all make an effort to participate in a World Congress and Melbourne 2014 will be a great opportunity to meet many wonderful people, who are part of this large haemophilia family.

PARIS, 2012

THE VIEW FROM A SMALL ISLAND

Jonathan Spencer is President of Haemophilia Foundation Tasmania and an Executive member of HFA Council. He has attended several World Congresses.

At the World Congress you have an opportunity to get involved in global issues and connect face-to-face. At a personal level, you think you have a rare bleeding disorder, and it is an amazing thing to meet someone who walks just like you, who has the same issues and the same dilemmas. In your local area you can feel very isolated. At these events, you realise there are many other people with bleeding disorders who have similar experiences – you can see that you are not alone.

I met some marvellous people there - amazing advocates, and they know how to party! They get fully involved in everything that they do.

A SPEAKER'S PERSPECTIVE

Dr Liz Bishop is the mother of two boys with haemophilia A, a member of Haemophilia Foundation Victoria and a medical ethicist. She had a poster on her experience as a mother with family centred care accepted

for a poster presentation at the Paris Congress.

It was hugely exciting to receive the news that my abstract was accepted as a poster presentation at the World Federation of Hemophilia Congress in Paris, but my expectations of the Congress itself were mixed. I was unsure what value it could have to me, let alone me to it.

Initially I introduced myself as just a parent. By the end I had shared the stories, experience and knowledge of many. My fondest moment was when the poster I had prepared brought tears to the eyes of another parent as we shared, momentarily, our stories. I was overwhelmed by how fortunate we are to have the access to treatment and trained medical professionals we have in Australia, which together with HFA and our various state associations such as HFV, represent our interests and positively agitate for change.

I have come away with a personal commitment to help boys with haemophilia and their families in other less fortunate countries to achieve equal benefits from progress within the haemophilia community. And, incredibly grateful for the experience. It took me 15 years to attend a conference and I exhort you all to make the most of an opportunity to experience one. Hopefuly Melbourne 2014!

WHAT'S IN IT FOR ME?

Claire Bell, the Haemophilia Clinical Nurse Consultant at Royal Perth Hospital, comments on the benefits of attending a World Congress.

The success of current haemophilia care globally is not all about factor concentrates, but that everyone is working together to improve quality of life for people with bleeding disorders - health professionals, people affected by bleeding disorders, pharmaceutical companies. By working together as a team, those affected have improvements in their lives, even if they still cannot access factor concentrates.

The World Congress is an opportunity for people living with bleeding disorders to come together and participate in that worldwide team. There are people to meet, lessons to be learnt and hopefully everyone goes back to their community with a renewed sense of wanting to participate and to continuously strive to increase quality of life for those affected, now and in the future. ■



Paris 2012

Above: Jonathan Spencer and Jurarat Suriyathai from Thailand at the 2014 World Congress stand

Middle: WFH Close the Gap booth

Below: HFA 2014 World Congress stand

WORLD AIDS DAY



World AIDS Day is celebrated globally on 1 December. This year, as we prepare for the World Hemophilia Congress in Australia in 2014, it is an opportunity to join with the international bleeding disorders community as well as the local community in Australia to show solidarity and raise awareness about HIV.

At this time we remember the community members who were affected by HIV when HIV was transmitted through some batches of clotting factor treatment product in the mid 1980s. As a result of this tragic episode, some people lost partners, family members, children, patients, colleagues and friends. Some people continue to live with the challenges of HIV and some to inspire by their positive attitude, resilience and determination to build a better future.

The HIV epidemic was felt in haemophilia communities around the world; in particular, in developed countries where people had access to clotting factor concentrates. It affected many people – including Frank Schnabel, a Montreal businessman with severe haemophilia A who had established the World Federation of Hemophilia in 1963. Before Frank died of AIDS in 1987, he continued reaffirm his vision to improve treatment and care for “the hundreds of thousands of haemophiliacs” worldwide through WFH with the words: “We are going to emerge victorious”. World Haemophilia Day is celebrated on 17 April, Frank Schnabel’s birthday, to recognise this vision and the ongoing commitment to make it happen.

2013 CAMPAIGN

In 2013 the World AIDS Day global campaign theme is:

Getting to zero

- Zero new HIV infections
- Zero discrimination
- Zero AIDS related deaths

In Australia, the aim is to encourage all Australians to be aware that HIV still exists in the community; to take action to prevent transmission of HIV by promoting safe sex practices; to support and understand people living with or affected by HIV; and to uphold their right to participate in the community free from stigma and discrimination.

This year World AIDS Day highlights the role of HIV positive people in strengthening community spirit. It is a reminder how important it is for people living with HIV to share their experiences and knowledge and educate others about HIV, resilience and the personal skills needed to adapt and manage hardship. This is particularly true of the bleeding disorders community where people may live with and manage multiple health conditions.

WORLD CONGRESS

The World Hemophilia Congress will include presentations and posters on the experience of HIV in bleeding disorders from around the world, with updates on treatment and care, quality of life issues and personal stories exploring how individuals manage living with HIV and a bleeding disorder.

AIDS 2014

In July 2014 the international AIDS Conference AIDS 2014 will also be held in Melbourne, Australia. More than 14,000 delegates from nearly 200 countries will come together - those working in the field of HIV, as well as policymakers, people living with HIV and others committed to ending the epidemic. It will be a tremendous opportunity for researchers from around the world to share the latest scientific advances in the field, learn from one another’s expertise, and develop strategies to advance all aspects of the collective efforts to treat and prevent HIV. There will be a strong emphasis on the approach in this region and the learnings from the Australian health policy response, which has been characterized as having a high degree of partnership between scientists, government and community. HFA will have a representation at this Conference.

For more information about AIDS 2014, visit www.aids2014.org. #

Suzanne O'Callaghan is Haemophilia Foundation Australia Policy Research and Education Manager and part of the MyABDR project team

MYABDR PROJECT UPDATE

Suzanne O'Callaghan

With its first release due in February 2014, the MyABDR project is moving ahead at a rapid pace.

MyABDR will be an exciting new online tool to help you record home treatments and bleeds, stocktake and update contact details using a secure app for smartphones and/or a computer web site. It will link directly to the Australian Bleeding Disorders Registry (ABDR), the system used by Haemophilia Centres for clinical care of their patients.

For people who prefer a paper-based recording system, this is also being developed alongside as an alternative.

As a collaboration between HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments, there has been a wide range of expertise and support to call on.

FOCUS GROUP

It has been important to involve people with bleeding disorders early in the development phase. The MyABDR community survey in July and August 2013 was followed by a focus group workshop in October. Seven individuals with diverse treatment experiences from around Australia met with the HFA and NBA MyABDR project team at a hotel at Melbourne Airport. Their job was to do intensive alpha testing – initial product testing of the first prototype – and give feedback on how it would work with their normal treatment and recording routines. There were lively discussions about many different

aspects of the prototype. The consensus was that the prototype was looking good and the technical team from the NBA took home detailed notes and suggestions on how to improve the functionality and the look and feel.

COMMUNITY TESTING

The NBA team is currently reworking MyABDR in preparation for the next step in late December 2013 – beta testing of the revised prototype to fine tune the detailed design and iron out bugs. A larger community focus group will be involved in beta testing on their smartphones and computers at home.

'A common theme in the workshop feedback was to include more default settings to make recording quicker and easier,' said Michael Linegar, MyABDR Project Manager at the NBA. 'We are keen to see if the default settings in the revised prototype will work well for a broader range of adults and children with bleeding disorders, including families with several members who need to record on the one device or login.'

If you are interested in home testing, please contact Suzanne at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173. There will also be another small focus group workshop for beta testing in early January 2014.

ABDR

Integrating MyABDR records into the patient record in the ABDR has been another challenge and a lot of work is taking place at the same time with

haemophilia health professionals, who have been advising the technical team on how to make the system work best for them and their patients. New menu sections, on-screen prompts and notifications for the ABDR, MyABDR registration procedures, and community education messages are all part of this work.

'We need to be careful not to confuse people. The message has to be clear that people should continue to contact their Haemophilia Centre directly if they have any concerns about a bleed,' noted Maureen Spilsbury, Advanced Social Worker – Haemophilia at the Queensland Haemophilia Centre. 'Although MyABDR will be an important recording tool for people and their Haemophilia Centre, speaking to the Haemophilia Centre will still be the first step if there is a problem.'

AN IMPORTANT TOOL FOR THE FUTURE

In a world where life is increasingly busy and managing a bleeding disorder can be complicated, MyABDR will have an important role to play in the treatment landscape of the future.

'As treatment plans become more individualised and new treatment products come into the market place, monitoring the effect of treatments closely will be crucial, not just for the individual but so that we can analyse collated results across our patients to understand and substantiate any benefits or adverse reactions relating to these products,' said Dr Simon Brown, Director of Haemophilia at the Royal Children's Hospital, Brisbane.

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AND NEXT?

At the recent annual HFA Council meeting - the second anniversary of the Council resolution to pursue a personalised online treatment recording system – the MyABDR project team gave an update on progress, complete with screen shots and discussion about functionality.

‘We were really impressed with how far the project has come in a short time with a very complex product,’ commented Shane Meotti, HFWA delegate. ‘There is a very disciplined approach to controlling the development and what will be in scope at each stage, which makes for confidence that the product will be delivered.’

Features in the first version of MyABDR will include:

- Default settings for recording treatments based on last details entered for each treatment type
- A body image to select the area of the bleed
- Detailed notes fields

- An easy to use inventory section to manage the stock you have at home
- Family logins that can switch between multiple family members
- Able to update height and weight, contact and delivery address details
- Screen displaying treatment plan
- Reports of treatment and bleed histories – these can be printed from the computer version.

Other features have been staged for the next versions of MyABDR. Some rely on projects that are currently underway - for example, a project to standardise barcodes, so that barcode scanning can be incorporated into the MyABDR product.

More information is available at www.haemophilia.org.au/myabdr. 

Abi Polus is the Senior Clinical Physiotherapist in Haemophilia at the Alfred Haemophilia Centre in Melbourne, Australia

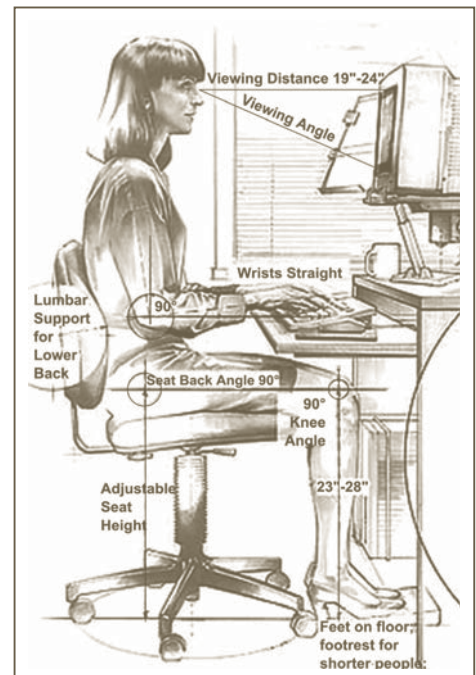
IN A SLUMP?

Abi Polus

Do you spend some or part of your day slumped at your desk or in front of a computer? Are you studying or working for hours at a time? Do you precariously balance your laptop on your knees?

For the majority of us nowadays, the majority of our time is spent with our ‘necessary equipment’ set up in

front of us, be that a steering wheel, a computer, a till, our tools, a television, a phone or even an old-school book. Both work and leisure for most of us, at least for part of the time, does involve at least a degree of forward posture. This is not unique to people with haemophilia but a world phenomenon. The consequences of



this - back pain, weak core muscles, tight and sore compensator muscles - are seen in both haemophilia and general physiotherapy clinics throughout the world.

CONSIDER YOUR WORKSPACE

Large companies usually have an access to occupational workplace checks so ask your boss if you can have someone come around to personally assess your workplace set-up. This does not have to be in the context of you having haemophilia, rather as looking after your muscles and joints. Otherwise there is a lot that you can change yourself.

Even just playing around and adjusting your desk/office chair to your own needs can make a huge difference. If you share space or chairs you should either re-adjust each time or consider labelling your own chair with a note not to readjust it. Buddy up with a work (or play) colleague and spend a minute critiquing each other's work posture and then adjust it.

The general rules of thumb are:

- You should be sitting and looking at you monitor straight-on with your eyes level to the top of the screen so that you can scan down without moving your neck.
- Your chin should be very slightly tucked in and not jutting out (this is a common reason for neck pain when the head is jutting out and straining forward).
- Your mouse and keyboard should be directly in front of you at elbow height and you should be able to access them both with bent elbows.

For people with haemophilia who have issues with their elbow this is even more imperative. Time that has been spent in slings, or protecting the elbow, can lead to an imbalance in the muscles surrounding the neck, shoulder and elbow. If combined with poor posture, for long periods of time at work or studying, at the computer or TV, this can lead to pain dysfunction.

- Your hips and knees should be at 90 degrees and feet flat on the floor.

For people with haemophilia who have issues with their knees and hips this will stop unnecessary strain and already tight muscles to become even tighter and overused, which again, can lead to pain and dysfunction.

- Your lower back should be well supported by the chair (a rolled towel in the small of your back will do the same, keep it on at work or in the car for long journeys). Many modern work chairs and car seats have these functions; spend a few minutes playing with your seat.

What follows are some helpful tips to make small changes that can make a large difference.

You do not need fancy and expensive equipment; a few books or The White Pages under monitors etc. can make a huge difference.

If you are working for significant time on a laptop do make sure that it is in a good position. Poor laptop position, especially if it is too low, you have to twist to it, or are balancing it on your knees, appear to be the biggest offender and precursor to pain at the moment!

The other common complaint is getting up from having sat in any position for a long period of time, particularly the impact on ankles and knee that have been affected by previous bleeds. To combat this, try to get up regularly, even if it is to walk around the office or room once, or stand and march on the spot and then re-sit - in a good position - without even breaking your concentration. This can aid better posture when you re-sit and stop some of those painful moments when you stand.

Exercises to do during work

- Set your watch alarm to go off hourly. When it does roll your shoulders down and back, tuck in your chin. Continue working.
- Without stopping working stand up and squeeze you gluteal muscles (bottom muscles) together for 5 seconds and release. Repeat 10 times. Sit back down in a good posture.
- In sitting, put your hand on your hips and tip/roll you pelvis

forwards and backwards keeping your lower back still.

- Have a small post-it note on your desk/computer that says 'posture'. Every time you glance at it sit up correctly.

Once you establish good habits it gets much easier to continue.

EXERCISES TO COUNTERACT THOSE USED IN FORWARD POSTURES

Use your deep neck flexor muscles (pull in - not down - your chin; imagine you are making a double chin) and also the extensor muscles in your back and shoulders (for example, used during rowing action). These will particularly help balance out the muscles used when bending forwards. You can include them into a gym routine or just do them regularly at home.

Swimming backstroke is a great way to exercise the opposite muscles you use sitting. 'Rowing' using a piece of theraband around a door handle (ask your local physio) is another great way to activate the opposite muscles to those you use sitting.

People with haemophilia may have more serious consequences of sitting in poor positions and potentially may have more prolonged healing times than people without haemophilia. It really is worth the simple steps of changing your mindset and challenging yourself to better your posture for a more comfortable life!

Good luck! 🍀



Megan Sarson is the AHCDO Project Officer

AHCDO UPDATE

Megan Sarson



Alison receiving the Barry Firkin Award from Huyen Tran

NEW GUIDELINES

The Australian Haemophilia Centre Directors' Organisation (AHCDO) has been busy collaborating with the National Blood Authority (NBA) to draw up a proposal to develop new factor VIII and factor IX treatment guidelines. The previous guidelines were published in 2006 so are well overdue for renewal. Due to the limited amount of clinical evidence, guidelines for bleeding disorders are usually consensus based and these new guidelines will be no different. The World Federation of Hemophilia (WFH) has recently published comprehensive guidelines (*Guidelines for the management of haemophilia, 2nd edition*), which cover all aspects of haemophilia treatment and care. The new AHCDO/NBA proposal is that we build on this existing resource by examining how care and treatment may differ in the Australian community, how treatment regimes may impact on product sustainability and we will also include a consideration of the variability of treatment with a potential for a consensus approach. The new guidelines should also consider any new or emerging policies and products within the Australian setting. Over the coming months AHCDO members will work together with

the NBA, HFA and various other stakeholders prior to a public consultation and then publication.

ALISON STREET PRESENTATION

Prof Alison Street, former Director of the Ronald Sawers Haemophilia Centre at The Alfred hospital, was invited to present the Barry Firkin Oration by the Australasian Society of Thrombosis and Haemostasis (ASTH) at the HAA conference (the joint annual scientific meeting of the ASTH, the Haematology Society of Australia and New Zealand and the Australian and New Zealand Society of Blood Transfusion), which was held recently on the Gold Coast. Barry Firkin was a haematologist whose work was critical to our understanding of the biology and biochemistry of von Willebrand factor. He became an inspiration to many Australian haematologists and is regarded as the father of modern Australian haematology. The Barry Firkin Oration is held in his honour each year and is given by an eminent haematologist - Alison certainly fits that criterion.

Alison delivered an enlightening talk entitled 'What a Difference Thirty Years Makes' in which she

gave an overview of haemophilia care and treatment over the past three decades. She mentioned the highs and lows of some personal, clinical and scientific issues, likening it to the European Thirty Years War, and also highlighted the continuing work done in Haemophilia Centres throughout the country, sharing photos of many Haemophilia Centre staff teams. Alison's involvement with WFH has also been extensive and she illustrated twinning schemes in both China and Viet Nam. Alison was presented with the Barry Firkin Award by Dr Huyen Tran, the new Director at the Ronald Sawers Haemophilia Centre and ASTH President. ❏

CHANGING POSSIBILITIES IN HAEMOPHILIA® GRANTS



Clare Hood and Claire Bell



Penny McCarthy

The Changing Possibilities in Haemophilia® grant program is to provide funding for four new projects. The grant program has been developed and funded by Novo Nordisk and in 2013 will award over \$50,000 for health professional projects designed to advance haemophilia care in Australia.

The independently adjudicated grant program, now in its second year, supports new projects and initiatives to be implemented by nurses, physiotherapists, psychologists and other professionals involved in haemophilia care.

Located in the Australian Capital Territory, Victoria, Queensland and Western Australia, the four initiatives and programs stood out from a competitive group of applications from haemophilia healthcare professionals across the country.

The recipients of the 2013 Changing Possibilities in Haemophilia® grants (in alphabetical order) are:

NORTH WEST WA EDUCATIONAL ENDEAVOUR - 'FROM THE METROPOLITAN TO REMOTE COMMUNITIES'

Lead Investigator: Claire Bell, Haemophilia Clinical Nurse, Royal Perth Hospital, Western Australia.

Second time grant recipient, Claire Bell, has been involved in a number of initiatives to improve health outcomes for people with inherited bleeding disorders. After years of working in remote communities in Western Australia, haemophilia nurse Claire Bell has recognised the impact of the reduced access to information and education for healthcare professionals and healthcare workers in North West WA.

"The distances in North West WA mean that it is not always as simple as sending a patient down to the metropolitan area for diagnosis or management, or that there will be considerable delays in doing so," said Claire. "It is critical that we ensure remote aboriginal communities and mining sites are provided with the necessary educational materials to provide optimal care."

Claire was supported in her application by Claire Hood, a haemophilia social worker.

A NURSE INITIATED MEN'S GENERAL HEALTH SCREEN

Lead Investigator: Penny McCarthy, Haemophilia Clinical Nurse Consultant, The Alfred hospital, Ronald Sawers Haemophilia Centre, Victoria.

For the past 15 years, Penny McCarthy has been working in caring with people with haemophilia and other bleeding disorders. From her experience, Penny has witnessed the under-appreciation by men of the importance of preventative health strategies. She has also recognised that men are reticent to seek timely health care and delay visiting a doctor until significant symptoms arises.

The aim of her project is to improve health outcomes for people with haemophilia by offering nurse initiated general health screens annually, whilst attending the Haemophilia Centre for routine appointments. The judges said Penny's project "is a very achievable and workable project that could be easily implemented into the existing hospital and clinic setting."



Dr Nalini Pati and The Canberra Hospital haemophilia team



Beryl Zeissink

THE HAEMOPHILIA TREATMENT CENTRE THE HAEMOPHILIA TREATMENT CENTRE (HTC) - REGIONAL OUTREACH PROGRAM

Lead Investigator: Dr Nalini Pati, Consultant Haematologist, The Canberra Hospital, Australian Capital Territory.

Dr Nalini Pati is the Consultant Haematologist at The Canberra Hospital. He has over 10 years' experience in the field of clinical haematology including haemophilia, a key member of the Paediatric Haematology Unit at the Royal Children's Hospital, Melbourne and alumni of Haemophilia Academy. His application was supported by The Canberra Hospital Health Services HTC Team, Katie Shoemark (database manager) Vanessa Minor (Haemophilia RN), Kathlene Robson (Haematology Outpatient CNC) and Clare Reeves (Counsellor for HFACT). Dr Pati says, "This is an important step in making services more accessible and available to clients and their families in a fairly isolated rural setting and reinforces the need for comprehensible care and ongoing contact with HTC staff."

EDUCATION FOR AN AGING HAEMOPHILIA POPULATION

Lead Investigator: Beryl Zeissink, Haemophilia Clinical Nurse, Royal Brisbane & Women's Hospital, Queensland.

Beryl Zeissink, a clinical nurse consultant at Queensland's Haemophilia Centre, has recognised the lack of education for the aging haemophilia population and, in particular, men.

"As these men age, health issues can be compounded by the need for invasive investigations, procedures and surgeries, potential development of inhibitors in men with mild haemophilia, and lack of ongoing contact with a Haemophilia Centre," said Beryl.

Beryl's project aims to develop targeted tools to meet the educational needs of men and GPs. The first stage of this project will be to assess the needs of the men with haemophilia, their GPs and the perceived needs of healthcare professionals from haemophilia centres. The findings will then be used to develop a tool, to assist men with haemophilia to have proactive discussions with their GPs about their general health, haemophilia and routine "Men's Health Checks."

For full details on the 2013 grant recipients and judges, please visit www.changingpossibilities.com.au.

If you would like to receive updates on the 2014 Changing Possibilities in Haemophilia® grants program, please email your details to the secretariat at info@cube.com.au #

"As these men age, health issues can be compounded by the need for invasive investigations, procedures and surgeries, potential development of inhibitors in men with mild haemophilia, and lack of ongoing contact with a Haemophilia Centre," said Beryl.

AUSTRALIAN/NZ HAEMOPHILIA SOCIAL WORKERS' AND COUNSELLORS' GROUP MEETING

Leonie Mudge

Ten members of our group were present for all or part of our day and a half meeting in Melbourne in October 2013. We really appreciate the opportunity to catch up annually face to face to share, to plan and to learn, which is organised through HFA.

The aims of our group include ensuring a high quality psychosocial service is available to people with inherited bleeding disorders and their families. The Australian members of the Group are almost all employed in a clinical role with the hospital social work department or the Haemophilia Centre. The New Zealand members of our group are employed by the New Zealand Haemophilia Foundation as Outreach Workers with a greater focus on home visiting and programs such as camps and workshops.

Some of the issues we discussed at our recent meeting included:

- A presentation on My ABDR from Elizabeth Arnold from the National Blood Authority and Suzanne O'Callaghan, HFA's Policy Research & Education Manager, who is a member of the MyABDR team. We were able to present the data entry needs of our group which will enable us to contribute to better outcomes for the bleeding disorder community through co-ordinated care within the comprehensive treatment team.
- We participated in a strategic planning exercise about our role within the treatment team. With assistance from an outside facilitator, Ralph Hampson, we were enabled to take a step back and reflect on our role, and share our perceptions of the current challenges and opportunities. We found it restorative and stimulating to think about how we juggle change and competing demands.
- We talked about the Parents Empowering Parents (PEP)

program. The course helps young parents establish a blueprint plan for parenting, enabling them to voice what their hopes and fears for their child are alongside working out what they need to do to support their child to become the adult they would like him/her to be. Participation in such a group helps young parents forge links with a support group which will provide ongoing sustenance through the parenting years ahead. Our goal is to have another PEP program in Australia.

- A pregnancy flow chart was tabled which had been developed in the Haemophilia Centre in WA. This guide encouraged all women with an inherited bleeding disorder to get in touch with their Haemophilia Centres early if they are contemplating a pregnancy, to ensure access to all options and the best possible care.

Our group is working on a couple of projects:

- Haemophilia Activities List (HAL) - this is a self-administered tool to provide people with bleeding disorders and their clinicians with feedback about how haemophilia related arthropathy can be affecting their ability to participate in a range of everyday activities.
- Residential Care Information Booklet – written to assist Residential Aged Care Facility staff to understand and safeguard the needs of residents with inherited bleeding disorders.

We all took turns to present a summary of our activities over the last year:

Highlights from New Zealand included a national Youth Camp, on a Navy theme. They had also run another PEP programme – their first in four years. There was a national Women's

Weekend, an Adult weekend and further developments with their Cambodian Twinning Relationship.

In Australia social workers and counsellors were also active in facilitating a range of peer support programs:

- ACT continued their 'Women's Wisdom' and 'Men's Wisdom' groups.
- In NSW there were support groups offered at Calvary Mater Newcastle, and recommenced at Sydney Children's Hospital at Randwick.
- Queensland staff developed an 'Enhancing Lifestyles' one day workshop.
- Victorian staff attended the 'Blood Brothers' youth camp.
- In WA staff continued to facilitate Carers and Partners groups, a Men's Breakfast and a Women's Breakfast.
- Our members in Queensland and WA are also involved in outreach, which is important in such large states.

Implicit in these programs are the needs of community members at different stages of the lifestyle. We are particularly mindful of the needs of those who have been affected by blood borne viruses. We believe in the value of support from others going through similar issues, as well as providing access to the latest treatment information.

Finally our group was quite pre-occupied with plans for the forthcoming World Congress to be held in Melbourne in May 2014. We were keen to assist preparations to ensure it is both welcoming and informative. It will be a wonderful opportunity to find out about care for people with bleeding disorders around the world, and we will encourage members of our community to attend. ■

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COLOURING IN COMPETITION

Haemophilia Foundation Australia has launched an exciting colouring in competition "What's your Dream". The competition is supported by the Octapharma Group.

The Colouring In Competition is open from 13/10/2013 to 17/04/2014 and to children from any country in the following three categories:

Category 1: children aged under 4 years

Category 2: children aged 5 to 8 years

Category 3: children aged 9 to 11 years

There are great prizes for each category including an iPod Nano, an Apple voucher or a Toys R Us voucher.

The colour in sheets will be judged at the 2014 WFH Congress in Melbourne from 11-15 May 2014.

A colour in sheet has been inserted in this edition of National Haemophilia. To download extra sheets and terms and conditions visit <http://www.haemophilia.org.au/eventsandawards/colouring-in-competition-2013-2014>

For more information contact HFA on hfaust@haemophilia.org.au or call 1800 807 173.



TRANSITION TO A NEW SCHOOL? GOING ON HOLIDAYS?

Sharon Caris

You are sure to have started planning by now if you have a child with a bleeding disorder who is starting at a new school or child care centre next year. An exciting life stage like this is also likely to be a significant event for everyone in your family, and it might also be the first time the child care centre or school has had a child with a bleeding disorder in their care. It will be important that carers have an understanding of your child's care needs and how to deal with any problems that might occur.

It may be helpful to provide general information about your child's bleeding disorder and how it is usually managed, and a specific plan for your child that carers and teachers can use for when your child is in their care. Your Haemophilia Centre health professionals can help you to plan a good transition for you and your child. HFA or your local Haemophilia Foundation can also provide printed materials that may assist.

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.

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. ■



2012 TWINS OF THE YEAR

The World Federation of Hemophilia's **Twinning Program** links patient organizations and treatment centres in developing and developed countries through exchanges, trainings, workshops, patient education, and other activities to improve treatment and care for people with bleeding disorders.



Hemophilia Organization Twins of the Year

VIETNAM – IRELAND

*Vietnam Society of Congenital Bleeding Disorders
& Irish Haemophilia Society*

Highlights:

- Volunteer development and fundraising workshops
- Chapter development initiatives
- Revision of organizational governance structures
- Educational activities about Vietnam with the Irish bleeding disorders community
- Advocacy for lower insurance co-payments
- Production of a photography book and video celebrating twinning partnership



Hemophilia Treatment Centre Twins of the Year

HANOI (Vietnam) – MELBOURNE (Australia)

*National Institute of Hematology and Blood Transfusion
& The Alfred*

Highlights:

- Two-day physiotherapy workshop and clinic
- Two-day nursing workshop
- Multidisciplinary symposium
- Symposium for hematologists and physicians
- Laboratory monitoring and coaching
- Nursing monitoring and coaching

On behalf of all of the partnerships around the world, the WFH thanks Pfizer for its exclusive ongoing support of the Twinning Program.



WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

MELBOURNE HAEMOPHILIA CENTRE TWIN OF THE YEAR

Congratulations to the team at the Ronald Sawers Haemophilia Centre at The Alfred in Melbourne for winning Twin of the Year in 2012!

AUSTRALIAN HAEMOPHILIA NURSES' GROUP – 25 YEARS ON

Beryl Zeissink

This year the Australian Haemophilia Nurses' Group celebrated their 25th Anniversary. We were very pleased to have Dawn Thorp, one of the original haemophilia nurses of the Group, come and reminisce about the "early days" of managed haemophilia care in what was then called the Haemophilia Foundation Australia – Nurses' Association. Twelve nurses attended that first meeting in 1988.

Most of the current nurses who make up what is now called the "Australian Haemophilia Nurses' Group" have been in their jobs less than 15 years. In our current work life, we all know that there has been lots of change in the last 10 years, moving to recombinant products, and hopefully in the near future to longer acting products. However, Dawn was able to put some of the many other changes in the world of haemophilia in perspective for us. In the early days, we did not have the Australian Bleeding Disorders Registry; Dawn had a rolodex with all her patients' names and phone numbers. Some nurses didn't have access to email, let alone a computer. There were no haemophilia nursing guidelines. It was in these early days, with great foresight, that Haemophilia Foundation of Australia wrote to the hospitals involved in haemophilia care, and invited a local nurse to attend the first haemophilia nurses' meeting in 1988.

The early aims of the group were "to establish a network of Australian Haemophilia Care Nurses", and to "provide a forum where nurses involved in haemophilia care can



meet to problem solve, expand their knowledge and gain support from each other". Today, these aims remain an integral part of the Group's current Terms of Reference, but really are a lot broader than those early days. We are honoured that we advocate for the haemophilia community in a professional capacity, and that our Group's opinions are sought by the National Blood Authority and Haemophilia Foundation Australia. Today our Group is made up of representation from up to 16 Haemophilia Centres with about 18 Executive Members and invitation open to further Associate Members.

We know there will be many other changes ahead of us, and are pleased to say we have a strong committed Group that will continue to move forward on this journey with you. ■



Above: Australian haemophilia nurses at the World Congress in Madrid, 1988

YOUTH AT CONGRESS

FUNDING AVAILABLE FOR CONGRESS PLUS A YOUTH MEET & GREET!

If you are a young person, or you know of a young person who might be interested in going to the Congress in Melbourne, HFA has some funding available to help people with registration, travel and accommodation costs.

The Congress starts with the Opening Ceremony in the evening of Sunday 11 May and runs through until Thursday 15 May. Congress is attended by people of all ages, including youth from different countries as well. It is a great way of meeting young people with bleeding disorders from other parts of the world. There are plenty of Congress sessions that cater for issues experienced by youth so it is well worth attending if you can.

If you want to know more about Congress, speak to someone at HFA, your local Foundation or at one of the Youth Catch Ups if you are going to any of these, as a few young people from around Australia have attended

Congress in the past (for example, see Rob McCabe's comments in the Congress article in this newsletter).

Sometimes people might think they won't know anyone at Congress or that they will feel a bit "out on a limb" if they go to the Congress on their own. But there is no need to worry about that because WFH has already received lots of registrations from young people attending the Congress!

YOUTH MEET & GREET

But HFA wants to make sure every Australian young person attending does know someone at the Congress and can hang out with them if they wish! So, we are planning a Youth Meet & Greet over the Saturday/Sunday before the Congress if we get sufficient numbers of people interested. Young people would come to Melbourne on the Saturday and participate in the Meet n Greet over the Saturday and Sunday and then go to the Opening Ceremony of the Congress on the Sunday evening

and attend Congress sessions through the week.

The Youth Meet & Greet would involve organised activities so that young people can get to know one another, have fun and also to get more info about how to make the most of the Congress experience.

Full and or part funding will be available for young men and women affected by bleeding disorders from around all Australia (generally, young people will be aged 18 or over to attend Congress).

We know it might be hard for some people to be able to make a commitment at this early stage, as some people will not be sure about their school, uni and work plans yet.

Even if you can't be sure, please let Sharon Caris at HFA know by email scaris@haemophilia.org.au or phone toll free 1800 807 173 by 20 December 2013 if you are interested so we can get an idea about numbers and make further plans. #

SOUTH AUSTRALIA UPDATE

TEAM.FACTOR 2014

Bupa Challenge Tour Adelaide
Friday 25 January

Cycling enthusiasts from around Australia and the world have registered to participate in the 2014 BUPA challenge tour on Friday 24 January 2014. Cyclists will have the opportunity to ride the same route as competitors in the 2014 Santos Tour Down Under. The ride will start in

Unley and finish in Victor Harbor. A total of 154.5km.

A team of 8 headed by Dr Simon McRae will participate in the tour as Team.Factor. The team is

Dr Simon McRae, Dr Uwe Hahn, Andrew Atkins, Donna King, Dan Drake, Phil Shaw, Phil Burke and Michael Townsend – all from the Royal Adelaide Hospital.

Last year the team completed the tour and raised a total of \$2,025. To support them contact Dr Simon McRae simon.mcrae@imvs.sa.gov.au or phone 08 8222 6840 or call HFA 1800 807 173 or email at donate@haemophilia.org.au.

Good luck to the team! #



Team.Factor in 2013

YOUTH NEWS

Want to know how the catch ups for young people are going? Here's an update from some of the young leaders and mentors ...



YOUTH CATCH UPS



NSW

The Youth Catch Up in August at O'Dea Reserve in Camperdown was a great opportunity for young people living with a bleeding disorder and their friends to meet.

"For me personally, it was a great chance to meet other young people living with a bleeding disorder. It was a really fun day, and I was able to make plenty of new friends. I'm really looking forward to the next event!" - youth leader

Keep an eye on the HFNSW web site (www.hfnsw.org.au) or Factored In to find out what else is going on.

WA

In October 2013 we held a youth group catch up at the AMF Bowling Cannington. We had a good turnout and 10 young people and one Foundation leader attended. The catch up was informal and fun and there was still plenty of time to interact with everyone during the bowling activity and during the half time break.

The youth that attended the catch up enjoyed their time bowling; we divided into two teams and played two games each. The activity was a lot of fun and it was good that it wasn't taken too seriously; however, we did have some good bowlers amongst us.

It was a good experience for the Organisers and Mentors and we hope this is the start of more to come.

It was also good to have some new people attend the event and get to know others that have the same or similar bleeding disorder as them.



CALENDAR

WORLD HAEMOPHILIA DAY

17 April 2014
www.wfh.org/whd

WFH 2014 WORLD CONGRESS

11-15 May 2014
Melbourne, Australia
www.wfh2014congress.org

HAEMOPHILIA AWARENESS WEEK

12-18 October 2014
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.



biogen idec

CSL Behring



Seasons Greetings

We wish you and your loved ones a very happy festive season.

Thank you for your support during 2013.

We look forward to our work together in the coming year to help improve the lives of people affected by bleeding disorders.

The HFA office will be closed from Tuesday 24 December. The office will reopen fully on Monday 6 January 2014. During that time if you have any queries or need to contact HFA, please note that messages left on the answering machine will be monitored. If you have an urgent matter please contact Sharon Caris on 0410419914.



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