National Haemophilia

Haemophilia Foundation Australia www.haemophilia.org.au

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WORLD HEMOPHILIA DAY / APRIL 17

APRIL 17

CONTENTS

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NEW STAFF

Kristine Robertson joined the team at Haemophilia Foundation Australia in March 2012. Kristine has taken up the role of Fundraising Manager and will be working to build HFA's fundraising activities, particularly direct mail campaigns.

With a strong background in not-for-profit fundraising and development, over the past 15 years Kristine has worked at a range of community organisations such as Odyssey House Victoria, the Asylum Seeker Resource Centre, Good Shepherd Youth and Family Services and Christian Blind Mission International and brings a wealth of experience to her role at HFA.

Prior to her fundraising positions, Kristine worked as a journalist and takes immense pleasure in using her writing skills to communicate the importance of causes to supporters and the general public.

"I think it's a real privilege to tell people about the projects and programs of the organisation that I'm working for and let them know about developments. I find it really rewarding to give supporters the opportunity to participate through giving and to help make some of the projects and programs that we want to get off the ground a reality."

Starting work at HFA has been a sharp learning curve. "I didn't know much about bleeding disorders before I came to HFA," says Kristine. "I had no idea how debilitating haemophilia used to be, back in earlier days, or how bleeds actually happen. Obviously there are a lot of misconceptions out there. For example, I had thought that only men could have a bleeding disorder, whereas clearly women can also have bleeding disorders. I have learned a lot already in my short time in the position!"

At present Kristine is focused on direct mail campaigns, attracting new donors and keeping supporters and donors up-to-date with what they are making possible through their gifts to HFA. "It's a tough economic climate, and it's so important to bolster HFA's financial position, so that we can be a bit more self-sufficient and continue fund the vital projects and programs that we run now and are hoping to run in the future."

Kristine is keen to hear from community members and supporters. "It would be great to have a chat with anyone who has ideas, or wants to give feedback or has any questions."

Kristine works Monday, Tuesday and Wednesday. She can be contacted at: T: 03 9885 7800 or toll free 1800 807 173 E: krobertson@haemophilia.org.au

Sharon Caris is Executive Director, Haemophilia Foundation Australia

NEW PATRON AT HAEMOPHILIA FOUNDATION ACT (HFACT)

Sharon Caris

A gathering was held at the home of Fred and Maria Wensing on 11 May for HFACT members to farewell Major General Peter Phillips who was stepping down after more than 20 years as Patron of HFACT. President of HFACT, Fred Wensing recalled that Peter Phillips had kindly responded to a call for people who could help the haemophilia community. At the time he said he was not sure what he could offer, and perhaps he did not expect to become the Patron for so many years, but his involvement became important both to HFACT and to HFA.

The new HFACT Patron was also welcomed at the social evening at the Wensings. Dr Richard Pembrey is well known to the bleeding disorders community as a former health administrator and treater. After he was welcomed, Dr Pembrey told HFACT members how privileged he felt to be able to be involved with the community in the role as Patron.

(L to r) Mrs Vivienne Pembrey, Dr Richard Pembrey, Major General Peter Phillips and Mrs Ros Phillips

Gavin Finkelstein is President, Haemophilia Foundation Australia (HFA)

FROM THE PRESIDENT

Gavin Finkelstein

NEW TREATMENTS

For many years we have talked about a cure for haemophilia – throughout my lifetime a cure has been "about 20 years away". But as we now see the outcomes of clinical trials in patients with haemophilia B[1] we can see that it is getting much closer to safe and effective gene therapy treatments that will cure haemophilia and give us hope for the future, and perhaps the need for new and complex decisions. There will be many questions - will they be affordable; will they be accessible? Nevertheless, they hold promise for the whole world. Will gene therapy treatments be more suitable in some communities than increasing access to clotting factor treatments?

It is also a time when we are seeing more clotting factor treatment products in development and apparently getting closer to the market. This will be a challenge for people with bleeding disorders, patient advocacy organisations, payers, regulators and governments. I am interested in how the availability of more manufacturers with more clotting factor treatments will impact on global supply and cost through competition.

David Page, Executive Director of the Canadian Hemophilia Society (CHS), recently published an article in the CHS newsletter *Hemophilia Today* in which he identified that there are 23 new therapies in development: nine for haemophilia B, eight for haemophilia A and von Willebrand disorder (VWD) and six bypassing agents for treating people with inhibitors.[2] Although many of these are in early stages of development and not yet being trialed in humans, David Page pointed out that we might be seeing some of these drugs by 2015. That is not very far away in anyone's terms. It raises all sorts of questions of whether they will be available and at what cost and benefit. In Australia I can see we will need to be vigilant. We will need to understand the benefits of the various options and make sure there are robust processes for assessing which products should be purchased so that Australians with bleeding disorders have access to the most suitable products for their treatment.

WORLD CONGRESS 2012

I will be representing HFA at the WFH 2012 World Congress and General Assembly of WFH in Paris in July. The Board will also be represented by Dan Credazzi, Ann Roberts and Jonathan Spencer. Jonathan Spencer will also be attending the National Member Organisation (NMO) Training which is held before the Congress. This is a great opportunity for NMOs to come together to share their experiences and learn from each other.

The Paris meeting is also very important for HFA to promote the WFH 2014 World Congress. We are already working hard to make the 2014 a great success for HFA and WFH. Sharon Caris (Executive Director) and Natashia Coco (Development Manager) are working to ensure we take every opportunity to promote the 2014 Congress and to fill our promotional booth in Paris with relevant information about Australia to encourage people to start planning for 2014. We will also have support from the Melbourne Convention and Visitors Bureau, and one of their marketing experts will come from London to help us throughout the Congress.

I look forward to bringing updated information about living with bleeding disorders from the Paris Congress. We are excited that our abstract for a poster on the HFA youth project has been accepted for the Congress.

REFERENCES

1 Nathwani AC, Tuddenham EGD, Rangarajan S, et al. Adenovirus-associated virus vector–mediated gene transfer in hemophilia B. New England Journal of Medicine 2011. DOI: 10.1056/NEJMoa1108046 – see article "Gene therapy trial shows promising results" on p. 5 of this issue of *National Haemophilia*

2 Page D. Products in the pipeline. *Hemophilia Today* 2012 Mar; 47(1):17.

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

TOWARDS A COMMON PURPOSE

Sharon Caris and Suzanne O'Callaghan

How can you make a difference at a national level when you are a small organisation representing people with a rare health condition?

To have a stronger voice, HFA's national work to represent people with bleeding disorders often involves collaborations or partnerships with other agencies where all work together towards common goals.

These advocacy collaborations or partnerships start when the group of agencies have identified a problem or viewpoint they all share. Their combined strength and resources are important if they want to make a difference to decisions or attitudes in government, health services, other bodies or the wider community.

For HFA, the decision to join an alliance with other agencies is not taken lightly. It results from preparatory research to understand how the issue affects the bleeding disorders community and how members would like to be represented, and discussions with the other agencies on the aspects where all have similar opinions and where they differ. Sometimes HFA and the other agencies will work on their common goals together and pursue their different positions separately.

HEPATITIS C TREATMENT

You may be aware that the new triple therapies for hepatitis C, where the protease inhibitors telaprevir or boceprevir are added to pegylated interferon and ribavirin, have shown a substantial increase in successful treatment rates for people with HCV genotype 1. For HFA this is an important result as many people with bleeding disorders have HCV genotype 1 and have previously had unsuccessful treatment or have delayed treatment until more promising treatment options were available.

These new treatments have been approved for clinical use in Australia by the Therapeutic Goods Administration (TGA) but are still undergoing assessment to see whether they will be listed on the Pharmaceutical Benefits Scheme and attract a government subsidy so that the cost is more affordable.

HFA was invited to attend a stakeholder meeting with the Pharmaceutical Benefits Advisory Committee (PBAC) in May 2012 to look more closely at the comparative treatment effects and costs of these triple therapies. Both HFA and AIVL (Australian Injecting and Illicit Drug Users League) represented the Consumers Health Forum of Australia and joined with representatives from Hepatitis Australia to speak about the perspectives of people living with hepatitis C.

For HFA, this involved preliminary work to review the general issues relating to the new therapies, hepatitis C, genotype 1, living with long-term hepatitis C infection, and the added impact of having a bleeding disorder. Risks associated with the treatments are also important: clinical trials have shown that some people may experience additional side-effects such as rash or anaemia, but also that the side-effects can be managed by hepatitis clinics along with other side-effects.

Are there any specific risks for people with bleeding disorders? This was a difficult question to answer as worldwide very few people with bleeding disorders have participated in clinical trials of the triple therapy treatments. When we explored this with clinicians in Australia and internationally, the consensus was that they had not seen any evidence of increased complications in people with bleeding disorders; there was a theoretical possibility that small numbers of people might experience unusual bleeds, eg in small joints, as with the HIV protease inhibitors such as Darunavir, but that these can be managed and that they would be watching for evidence of these. Overall the treatments could have great benefit for some people, particularly those with more advanced disease, such as cirrhosis.

The PBAC stakeholder meeting was a valuable opportunity for HFA, AIVL and Hepatitis Australia to represent the perspectives of people with hepatitis C to government – and to confirm that we held common views.

HEPATITIS C FINANCIAL ISSUES

In contrast, HFA has needed to take up some concerns about hepatitis C independently. For several years HFA has worked to raise the issues that affect people with bleeding disorders who acquired hepatitis C through their treatment products with governments. These issues relate specifically to the complications of living with both a bleeding disorder and hepatitis C and the financial difficulties that result.

HFA made a submission to the 2004 Senate Inquiry into Hepatitis C and the Blood Supply and over the last couple of years has had ongoing correspondence and meetings with governments about these issues and about the HFA proposal for a financial assistance scheme. More recently HFA

has consulted again with community members and health professionals for more detail on problems people experience, particularly with out-of-pocket health care costs, and what might help.

The impact on individuals is severe and the need to address it is urgent, with many experiencing deteriorating health and struggling to deal with financial costs and access to government assistance, or missing out on essential health care because they cannot afford the costs. This can be as significant as access to fibroscan tests, a non-invasive test to monitor liver health, if the tests are only available in local private clinics, or delaying treatment because of they cannot afford to stop working. Many people with bleeding disorders are not eligible for financial safety nets such as insurance or government schemes due to the combination of their bleeding disorder and hepatitis C. HFA expects to meet with the federal government again in the near future to discuss this further and work towards finding a solution.

BLOOD SECTOR POLICY

Another area where collaboration and communication is important is in the area of blood product policy. Although HFA might at times have very different views about a government policy position and may actively advocate on behalf of its members for a different policy, there are also many instances where HFA works with other stakeholders for shared outcomes.

An important focus for HFA is on the safety, supply and availability of treatment products used by people with bleeding disorders. For example, the Australian Bleeding Disorders Registry (ABDR), which grew from a small database funded by HFA so that clinicians could collect information about their treatment of people with bleeding disorders, is now in a new phase of redevelopment that will mean we have more valuable data to help with clinical management as well as help other stakeholders to do their work. The Australian Haemophilia Centre Director's Organisation (AHCDO) takes a lead role in identifying the data to be collected and AHCDO, other health professionals groups, and organisations such as HFA can also use the data to understand more about treatment outcomes and for research.

One of the roles of the National Blood Authority (NBA) is to plan and manage the purchase and supply of clotting factor. The NBA needs to know how many people will need clotting factor and they use the aggregated data of individuals in the ABDR to forecast the likely demand and ensure government funding is available to cover the cost of the product needed for everyone in Australia to have the treatment they need.

Outside of Australia, the ABDR data is used in a joint effort by HFA, AHCDO and the NBA to provide input to the World Federation of Haemophilia (WFH) Global Survey. Many organisations, including patient organisations and governments around the world use this data to compare the number of patients treated and the type and amount of clotting factor used for benchmarking and advocacy for improved care and treatment in their own country and others.

This article is abridged from an article published on the World Federation of Hemophilia web site www.wfh.org. in December 2011 and is reprinted with permission

GENE THERAPY TRIAL SHOWS PROMISING RESULTS

The first unequivocal evidence of success in gene therapy for hemophiliaB was published in the *New England Journal of Medicine* in December 2011. Six patients with severe hemophilia B responded to injections of a normal factor IX gene. The first patient treated with a low dose injection has maintained levels of 2% for more than 16 months while another patient receiving the highest dose maintained levels that fluctuated between 8% and 12% for 20 weeks. All six patients showed benefit from the factor IX gene administration.

According to the researchers, "this study documents a critical step toward [eliminating the need for long-term intravenous infusions] and shows that sustained therapeutic expression of a transferred factor IX gene can be achieved in humans." The study concluded that "this gene-therapy approach, even with the associated risk of transient hepatic dysfunction, has the potential to convert the severe bleeding phenotype into a mild form of the disease or to reverse it entirely."

REFERENCES

1. Nathwani AC, Tuddenham EGD, Rangarajan S, et al. Adenovirus-associated virus vector–mediated gene transfer in hemophilia B. New England Journal of Medicine 2011. DOI: 10.1056/NEJMoa1108046

APRIL 17

WORLD HAEMOPHILIA DAY

WFH estimates 1 in 1,000 women and men has a bleeding disorder. However, 75% still receive very inadequate treatment or no treatment at all. What will it take to close the gap?

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

On World Haemophilia Day in Australia we asked people to **Wear Red** and to raise money for the World Federation of Hemophilia (WFH) to close the gap for international projects.

The aim of the WFH Close the Gap campaign is to improve accessibility and quality of care worldwide so that Treatment for All becomes a reality.

We are pleased to say that Australia raised $1500 for WFH Programs. Thank you to all who supported this very important cause.

World Haemophilia Day was started in 1989 and the World Federation of Hemophilia (WFH) chose April 17 in honor of WFH founder Frank Schnabel, who was born on that day.

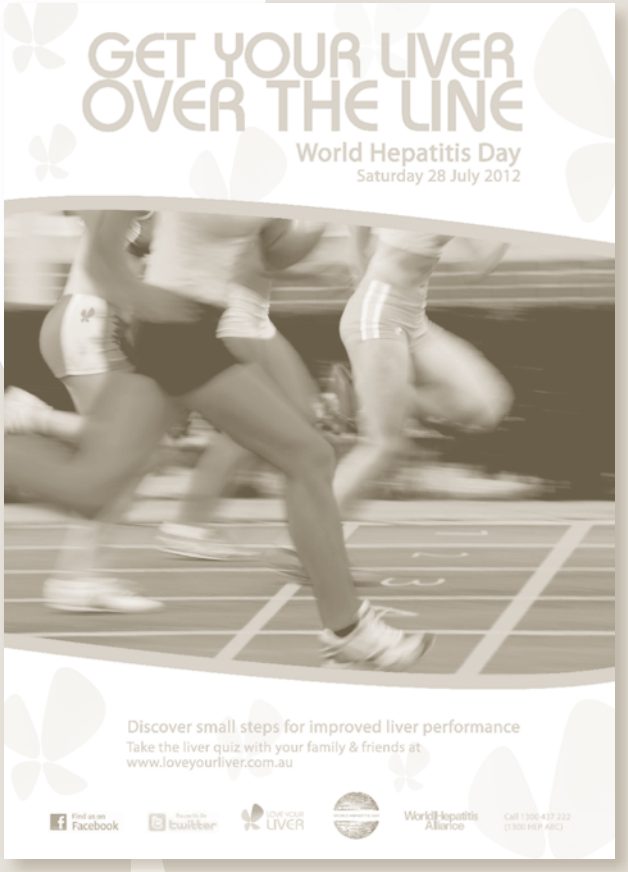
For more information on the WFH Close the Gap campaign, go to http://www.wfh.org/whd/en/

WEARING RED FOR WORLD HAEMOPHILIA DAY

Around Australia "wearing red" took a variety of guises:

- The HFA Executive Board and Staff wore red for the HFA Board Meeting.
- Australian Haemophilia Centre Directors' Organisation (AHCDO) wore red at the AHCDO meeting
- Sharon Caris, HFA Executive Director attended a sausage sizzle held for all staff at Baxter Healthcare. Staff made a gold coin donation
- Pfizer Australia had a guessing competition whereby colleagues guessed the number of "platelets in the large test tube". It was a fun way to get the message across
- Hepatitis Queensland staff wore red to work
- The Bates family in Victoria organised a dinner for friends and asked everyone to wear red. This was a most successful evening.

WORLD HEPATITIS DAY



WORLD HEPATITIS DAY WILL BE CELEBRATED GLOBALLY ON 28 JULY 2012.

The Australian theme this year is **"Love Your Liver on World Hepatitis Day"** and the aim of the national campaign is to raise awareness of liver health with the general community and present viral hepatitis B and C neutrally as health conditions linked to liver health. The intention of this is to normalise viral hepatitis and reduce stigma.

HFA is a Partner in the national World Hepatitis Day Campaign and has been working with Hepatitis Australia on the annual national awareness campaign around hepatitis. The national campaign poster has an Olympics theme, with the tagline **"Get your liver over the line"**.

There are a number of resources and merchandise, which are available from local Hepatitis Councils:

- World Hepatitis Day Posters
- Love your Liver pens, temporary tattoos, badges, stickers
- State-based resources, such as posters and postcards

WHAT CAN YOU DO TO BE INVOLVED?

- Visit the Lover Your Liver web site (www.loveyourliver.com.au)
- Download liver-friendly recipes from the web site – or add your own!
- Take the liver quiz on the web site
- Encourage friends, family and work colleagues to take the liver quiz as well
- Join the Love Your Liver facebook page
- Display the World Hepatitis Day poster at your workplace
- Attend a World Hepatitis Day or Love Your Liver event – check with your local Haemophilia Foundation or Hepatitis Council for details

Join HFA in making a difference on World Hepatitis Day.

Be committed to reducing hepatitis C stigma and discrimination and improving liver health in Australia and be involved in 2012!

...the aim of the national campaign is to raise awareness of liver health with the general community and present viral hepatitis B and C neutrally as health conditions linked to liver health.

Dr Jeffrey Grierson, Rachel Koelmeyer and Professor Marian Pitts are members of the Tracking Changes Research team at Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University, Melbourne

TRACKING CHANGES HIV STUDY RESULTS

Jeffrey Grierson, Rachel Koelmeyer and Marian Pitts

The key aim of the Tracking Changes study was to develop a deeper understanding of the experiences of people living with HIV (PLHIV) and HIV clinicians [doctors] starting and switching antiretroviral treatment (ARV) fifteen years on from the introduction of highly active antiretroviral therapy (HAART).

The Tracking Changes research team at the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University, Melbourne, conducted an online survey of PLHIV and structured qualitative interviews with HIV S100 prescribers [doctors who prescribe HIV medications].

THE KEY FINDINGS FROM THE STUDY WERE:

The relationship between clinician and PLHIV is a critical component of the processes of starting and switching ARV treatment. Clinicians are keen to involve PLHIV in the decision-making process and PLHIV have a high degree of trust in their clinicians' knowledge and judgement

- 75.9% of PLHIV who had at some point changed treatment reported that their doctors' advice was a very important factor in that decision
- Two-thirds of clinicians reported some involvement of PLHIV in decisions related to starting or switching ARV, with a third reporting that the patient had the final say
- HIV S100 prescribers play a very important role in the lives of PLHIV: PLHIV rely on their doctors for information about HIV and ARV, and the social aspects of the clinical encounter are rated highly by PLHIV
- 88.0% of PLHIV rated clinical sources as a very important source of information about ARV
- 82.4% of PLHIV rated clinical sources as a very important source of information about HIV
- PLHIV regularly cited the interpersonal style of HIV S100 prescribers as being the best thing about their clinical relationship
- Psychosocial factors play a major role in the processes of commencing and changing ARV
- Psychosocial factors such as patient concerns about side effects, the prospect of life-long treatment and patients' perceived readiness to commence ARV were among the barriers to commencing ARV most commonly mentioned by clinicians
- Perceived patient resistance to change and their fear of the unknown were the barriers to changing ARV most commonly mentioned by clinicians
- PLHIV attitudes towards starting and switching ARV mirrored the psychosocial aspects of starting and switching ARV that were described by HIV S100 prescribers
- Overall, the findings of the online survey and clinician interviews showed a high degree of consistency, indicating that HIV S100 prescribers had a good understanding of the needs and experiences of PLHIV.

We wish to thank the study participants for sharing their experiences with us, Gilead Sciences for funding the study and numerous HIV sector organisations for assisting us with recruiting participants for the study.

LIVING WITH VON WILLEBRAND DISORDER - *JENNA'S STORY*

Jenna is a young Australian woman with von Willebrand disorder (VWD)

I was diagnosed with VWD when I was 16 years old. After a few years of heavy, erratic and uncontrollable gynaecological bleeding, it was decided I needed some medical advice. My periods, much like for other family members, were severe enough that I spent time at home for each of them and unknowingly battled anaemia for the best part of 3 years. I found the dizziness I experienced as a side effect of anaemia could be quite debilitating. While other females in my family had experienced similar gynaecological symptoms, I was the first to be diagnosed.

I had also experienced frequent and long lasting bruising, the occasional nose bleed, anaemia and other symptoms of VWD, but compared to my more boisterous brother my occasional injuries were not seen as that serious. The diagnosis was a relief, as it gave me a reason for my bleeds, as well as my other symptoms. The only other treatment members of my family had received for bleeding before my diagnosis was surgical treatments for gynaecological bleeds (which in hindsight was quite dangerous without the VWD diagnosis). I have a brother, but he 'won the genetic lottery' and does not have VWD. There are currently no other members of my family who experience difficulties with VWD.

Like many people with bleeding disorders, finding the right medical treatment option is not straight forward. My gynaecologist suggested starting me on tranexamic acid, which prevents the breakdown of clots that have already formed, and combining this with a contraceptive pill to help control my gynaecological bleeding, but finding the right pill to use along with it was not an easy process. My periods are so heavy and long that just using the tranexamic acid is not enough to control them, but it took four tries to find a pill I respond to (including one option that made me bleed even worse than I do naturally!). Getting treatment for this symptom was certainly the hardest and the most concerning for me, and since then I've learned how to treat a range of other bleeds such as nose bleeds, bruising and external bleeds, and I've gone through DDAVP testing and learned how to self-administer it.

The one area I'd love to find out more about is managing pain – I still require pain relief for my gynaecological bleeding, but the options are limited. I can't use anti-inflammatory drugs like Naprosyn that other women use because they decrease clotting ability. Although they recognised that my pain levels were high, when I was diagnosed my doctors did not want me to use the painkillers available on prescription at this stage in my life, because putting someone on heavy painkillers for 20 or more years is not a viable option due to issues of dependence. Instead my haematologist and my gynaecologist wanted to try other options such as contraceptive pills and tranexamic acid to see if by using them and reducing my bleeding and hormonal symptoms my pain levels would also reduce. I currently use an over-the-counter drug balanced with increased levels of tranexamic acid to deal with pain (under the supervision of my medical team). I certainly don't experience as much pain now, although it does usually require some medication, and I'd love to know if there are other over-the-counter options that don't decrease clotting ability.

The biggest challenge for me as a teenager and still to this day is not coping with my symptoms, but feeling isolated. Despite my involvement with both the national and local haemophilia foundations, I am yet to meet other girls and women with my diagnosis. I have had support through life – my family, a teacher in high school, some friends and my partner - but none experience bleeding difficulties themselves. I strongly believe that the ability to share experiences and have someone to talk to who can really understand would have made a difference to my life, and will hopefully do so in the future.

I strongly believe that the ability to share experiences and have someone to talk to who can really understand would have made a difference to my life, and will hopefully do so in the future.

Another challenge, especially in years gone by, was being able to recognise that my gynaecological bleeding was not classed as medically normal, and that I didn't have to force myself to cope the same way as my peers in high school were able to cope with menstruation. I think this a major point of difference for women with bleeding disorders – while other bleeding disorder symptoms, like joint bleeds, are clearly not a normal human experience, menstruation is a very normal experience. I found it was easy

for me to think that I should be able to cope better as all women have menstrual bleeding and most don't need medication or time off to cope.

Problems I may experience in the future include having to come off my medication when I want to get pregnant (quite a frightening prospect), as well as raising a child with a bleeding disorder – because I have VWD, I have a 50% chance of passing it on to each child (compared with the 25% for haemophilia). I'm actually looking forward to providing support and mentoring either my own children or others in the bleeding disorder community as it was the type of support I didn't have growing up.

I'm also hoping to have to opportunity to network with other women with bleeding disorders. I hope HFA will one day have the resources to be able to better educate the medical community and better connect women with bleeding disorders so the feelings of isolation and fear won't be a reality for the next generation. I would strongly recommend other women who have a bleeding disorder to become part of their haemophilia foundation and to remain connected and informed so greater opportunities for sharing and support are available.

VON WILLEBRAND DISORDER (VWD) - SPECIAL ISSUES FOR WOMEN AND GIRLS

Heavy bleeding with menstrual periods (*menorrhagia*) is a common symptom of VWD for women and girls. It may involve:

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

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

Some women and girls with VWD also experience:

- Pain during their menstrual periods (dysmenorrhoea)
- Abdominal pain and sometimes bleeding during ovulation (when an egg is released from the ovaries, around the middle of the menstrual cycle).

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

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

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

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

HOW IS THIS TREATED?

With diagnosis and appropriate treatment, these problems can be dramatically reduced and sometimes even eliminated. Women who have menorrhagia or abnormal vaginal bleeding need a full gynaecologic consultation before treatment to understand any gynaecological issues.

Bleeding disorder treatments for heavy menstrual bleeding include:

- Tranexamic acid and aminocaproic acid, antifibrinolytic drugs which can reduce bleeding by slowing the breakdown of blood clots

- Oral contraceptives ("the Pill") combining the hormones oestrogen and progesterone. The hormones increase VWF and factor VIII in the blood and reduce menstrual blood loss. Although it also has the effect of preventing pregnancy, in this case the treatment's aim is to manage VWD symptoms and so it may also be suitable for teenage girls who are not sexually active and women who are not specifically seeking birth control

- An intrauterine device (IUD), releasing the hormone progesterone which reduces bleeding

- Desmopressin (DDAVP), a synthetic hormone which stimulates the body to release VWF and factor VIII

- Clotting factor concentrate made with von Willebrand factor (VWF) and factor VIII (FVIII), which replaces the missing VWF and FVIII in the blood and helps blood to clot. This clotting factor concentrate is made from the plasma (pale yellow fluid part) in human blood and is produced from blood donations. This clotting factor concentrate is used in uncommon circumstances, such as when other treatments have not been effective, and when the woman is trying to become pregnant, or when it is likely the person will need treatment for more than 2-3 days, and in discussion with the specialist haematologist at the Haemophilia Centre. The treatment is infused (injected) into a vein in the arm

- Iron supplements for anaemia.

Women with bleeding disorders should avoid taking non-steroidal anti-inflammatory drugs for period pain, unless prescribed by a doctor with expertise in VWD (ie, Naprosyn/naproxen, ibuprofen, etc – these have many brand names; ask your local pharmacist to check for you). These medicines can interfere with the way platelets promote clotting and cause bleeding to go on for longer.

Generally, treatment options with medication will be exhausted before considering surgery such as hysterectomy (surgical removal of the uterus) or procedures such as endometrial ablation, where the lining of the uterus is destroyed to reduce menstrual blood loss. Surgery and some procedures have their own risk of bleeding complications for women with VWD.

However, some women with VWD may need to have gynaecological surgery or procedures for other reasons. If this happens, it is important that this is managed in a team, with discussion between the woman, the Haemophilia Centre and the gynaecologist and/or surgeon.

HOW MIGHT THINGS CHANGE OVER A LIFETIME?

Puberty: menstrual bleeding can be especially heavy when a girl first starts having periods. When there is a family history of VWD or it is known that she has VWD, a girl should be followed closely by her medical team during puberty and may need treatment if she has heavy bleeding.

Sexual intercourse: some women with VWD may experience bleeding if there are small tears in their vagina after sexual intercourse. This can happen during their first sexual experience when the hymen is broken. It can also occur after childbirth and menopause when the vaginal wall may be thinner and dryer due to a drop in oestrogen levels - oestrogen creams for the vaginal wall and/or lubricants can help with this.

Pregnancy and childbirth: most women with VWD do not have a problem with delivering a healthy baby. Pregnancy can cause blood levels of VWF to increase, decreasing the likelihood of bleeding complications during pregnancy and delivery. However, this needs to be monitored as women with VWD can have heavy bleeding for an extended period after delivery when their factor levels return to their usual levels.

To minimise the chances of complications:

- Discuss VWD with a genetic counsellor, your haematologist

and an obstetrician before you become pregnant

- Before you have any invasive procedure, such as amniocentesis, ask your haematologist if you are at risk of bleeding and whether anything needs to be done to prevent it

- During your third trimester, you should have blood tests to measure VWF to help plan for delivery and for any treatments to prevent potential post-delivery bleeding

- Discuss your choices for anaesthesia, especially an epidural, with your haematologist, obstetrician, and if possible, your anaesthetist

- Unless prenatal testing has shown the opposite, it should be assumed that the baby may have VWD and delivery methods should be as gentle as possible. A caesarean section is not usually required.

Menopause: When a woman begins menopause, her body's erratic hormone regulation can increase her risk of unpredictable and heavy menstrual bleeding. However, for some women with VWD, levels of VWF rise as they age and normalise so that bleeding problems reduce. Keeping a close relationship with her gynaecologist in the years before menopause will help a woman with VWD be prepared to manage any problems that might occur.

MORE INFORMATION

To understand more about these issues and options and how they relate to your specific situation, talk to your specialist Haemophilia Centre team.

Resources for women with bleeding disorders:

Canadian Hemophilia Society *Coderouge* program for women and girls - http://www.hemophilia.ca/en/women/

UK Haemophilia Society *Women bleed too project* - http://www.haemophilia.org.uk/Our+help/Women.

HFA WOMEN'S PROJECT

Jenna's story about living with von Willebrand disorder in this issue of *National Haemophilia* reminds us how important it is for women to connect with each other by sharing their stories and realising that they are not alone in their experiences – and that having a bleeding disorder is something that can be talked about.

HFA is going ahead with its work on resources specifically for women, which will include personal stories and information answering women's questions.

There will be two new resources:

- Carrying the gene (haemophilia and VWD)

- Living with bleeding symptoms.

HOW TO BE INVOLVED?

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

- Participate in the HFA women's resources review group. This involves contributing ideas on what should go in the resources, reading over drafts of the resources and giving your comments

- Tell your story and have it included in the new resource (and *National Haemophilia*) – it can be anonymous if you prefer – and you can write your story yourself or be interviewed over the phone.

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

- socallaghan@haemophilia.org.au, or

- phone 1800 807 173

Check on the HFA web site under Bleeding disorders > Women with bleeding disorders for updates on the Women's Project - www.haemophilia.org.au.

Kate Walton is Haemophilia Foundation Australia Youth Project Officer

HFA YOUTH PROJECT UPDATE

Kate Walton

The HFA *Beyond Prophylaxis* youth project started in April 2011. There is little information about the impact of bleeding disorders on young people in Australia and the project will assist in better understanding the needs of young people. The aim of the Beyond Prophylaxis project is to enable young people to make positive and informed choices about their lifestyle and involves creating some communication and education resources to respond to their needs.

YOUTH WORKING GROUP

A key component throughout the whole project has been the Youth Working Group (YWG), which is made up of young people affected by bleeding disorders, carriers of the gene and siblings. There are young people from every state in the YWG, except the Northern Territory.

The YWG have provided direction from the beginning of the project by suggesting issues that need to be addressed on the website when they participated in the needs assessment. The group of young people who attended the weekend workshop in February worked with the design company to develop the concept and design of the website to ensure it meets their needs and expectations.

The YWG continues to play an active role in the project. They have been asked to suggest names for the site, write personal stories, recruit new members and have had a role in the planning for the promotion and launch of the website. YWG members who attended the weekend workshop have completed a survey to ensure future youth activities are youth friendly. The YWG have also evaluated the website and provided important feedback which has been taken into account before the site goes live.

YOUTH WEB SITE

The development process for the website started in March, after the Weekend Workshop with the YWG. This was to enable the ideas and preferences of the YWG to be taken into account when designing the site. The design company has spent several months working with me on these ideas and preferences to design and develop a suitable look and feel for the website. We focused on making the website bright, fun and easy to use.

The name of the website is 'Factored In' and it will be launched on 26 June 2012. The website will be available for everyone to view and we invite you all to jump on the site and have a look around. Apart from the obvious play on words in the title of the website, we are hoping that young people will have *factored in* the information on the website before making life and lifestyle choices. We also hope that they can see their stories and perspectives are *factored in* to the primary purpose of the website - providing education and support. The website is designed to be a constant work in progress as young people are encouraged to join up to the site and post stories and videos about living with their bleeding disorder, being a carrier or a sibling. Young people can also comment on each other's posts and ask questions to an expert and have it answered (remaining anonymous, if they wish). The more young people who join up to the site and share their stories, the more effective the website will become as a learning tool for young people as they will begin to gain knowledge from each other's experiences. The website is going to be a fantastic resource and we encourage everyone to utilise it.

NEEDS ASSESSMENT REPORT

After the preliminary needs assessment report in January 2012 pointed to the need for further consultation, younger people and parents were recruited and the final report will be available shortly. Twenty six young people answered the consultation questions with ages ranging between 13-27 years old. Nine parents also took part in the consultation process, along with all Foundations and 16 health professionals. Evidence from the Needs Assessment suggests further work is needed in the area of youth engagement and in particular the development of young people with bleeding disorders as peer educators and mentors.

NEXT PHASE

HFA has received funding from the Department of Health and Ageing to continue the project based on the recommendations of the Beyond Prophylaxis project. The next stage of the project will be to develop a leadership and mentoring program for young people affected by bleeding disorders which takes into account the complexities of their communication, support and education needs. The program will focus on youth mentors and leaders developing content for the youth web site and an ongoing national youth camp/workshop.

I will work with young people, local Haemophilia Foundations and health professionals to identify young members of the community who would be suitable for youth leadership and mentoring roles. A national youth camp/workshop activity which includes a component for promoting sustainable leadership and mentoring, will also be developed and piloted e.g. with skills-based sessions around peer education and mentoring.

FACTORED IN

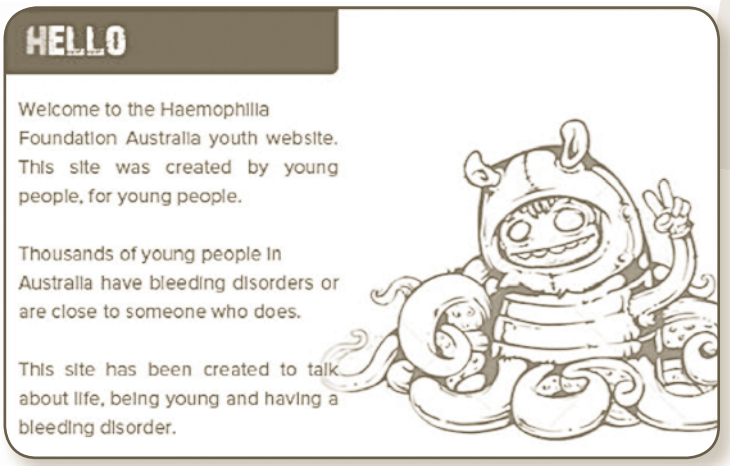
FACTOREDIN.ORG.AU

"Don't use medical mumbo-jumbo"

Got some questions?
What does the new HFA youth website look like?
What information is on it?
What did the Youth Working Group say?
Get some answers!

"Keep it Simple"

"Tips for injections"



"Use dot points"

"The possibility of a cure, I keep hearing that one is coming in the next ten or 20 years, or that it's just around the corner, when will it get here? And what could it involve?"

"Stigma of having a disease"

"Being isolated from friends"

YOUTH NEWS

"Bold and in your face"

"Restriction of future employment"

"I'm a very visual person so video and video diaries would be great"

"More visual – videos, pictures"

"Finding out about being a carrier"

"Real stories of others dealing with the disorder"

"Tips for injections"

"What I do like in a website is a good user interface which is easy to understand and navigate"

"What/if anything that will happen during puberty and adolescence?"

"Not just haemophilia, not just boys"

"Emerging treatment options"

"Educating my school and my classmates/friends with what the disorder is, and that I won't die if I get cut etc."

FACTORED IN

FACTOREDIN.ORG.AU

PLACE POSTAGE HERE

Dear Reader,

You're invited to the online launch of the new HFA youth website "Factored In"

Date: Tuesday 26th June 2012

Address: www.factoredin.org.au

Time: 1 pm onwards

Dress: formal

Grainne Dunne is Clinical Nurse Consultant Apheresis/Haematology at Sydney Children's Hospital

TRANSITION - MAKING THAT MOVE

A young man with haemophilia and his family celebrate his graduation from Sydney Children's Hospital to The Prince of Wales Hospital, Randwick, Sydney.

Grainne Dunne

Change is often a difficult or daunting process for everyone, whether it's changing how we do things, changing where we live or changes in work.

For our long term paediatric patients, changing hospitals is inevitable once the patient is old enough to move on to the 'adult' world of health care. For these 'young adults' such a transition involves 'changing how they do things' as well as 'changing their hospital location'.

Over the past few years, our haematology department at Sydney Children's Hospital has worked hard to improve how we manage these important life changes for our teenage patients. Most of these patients have thalassaemia, haemophilia, sickle cell anaemia or other blood disorders where they have been reliant on the children's hospital for as far back as they can remember.

GRADUATION CEREMONY

For the patient and their families moving on to adult care is a new and sometimes difficult challenge - one not to be taken lightly. The patient and their family worked hard managing their health care through long years of attachment with Sydney Children's Hospital. When they reach this point of transition, they are entering into a new era of their lives. Sydney Children's Hospital recognised the need to reward these patients for all their long years of hard work and to celebrate this transition point of moving to adult healthcare and achieving greater independence. For this reason, Sydney Children's Hospital hosts a Graduation Ceremony twice a year for long term patients who are now ready to move to adult health care.

The graduation ceremony is intended to be a memorable occasion providing a way to say goodbye to the old and to greet the new.

A recent example of this is the graduation that was held in May 2012. One of the patients has haemophilia A and graduated to The Prince of Wales Hospital Randwick early this year. He and his family together took part in the graduation ceremony at Sydney Children's Hospital..

The ceremony was hosted by Sydney Children's Hospital Director of Clinical Operations Michael Brydon together with 'Captain Starlight' and 'Captain Sidepony'. The Captains are funny and entertaining "superheroes", who are part of the Starlight Foundation programs at several of the children's hospitals around Australia, including the Sydney Children's Hospital. Many of the graduates knew the Captains from the Hospital, where they had encountered them in previous ward visits, on their interactive and amusing hospital channel and in the Starlight Express Room for young patients and siblings at the Hospital. Their presence at the ceremony was to lighten the atmosphere and bring humour to the 'show'.

All three provided enough humour to lift everyone's spirits if not the ceiling itself. The invited celebrity speaker, Shannan Ponton, who is well-known for his role as a trainer on the Australian television show "The Biggest Loser", was amazingly inspirational as he congratulated the graduates on their wonderful achievements and provided great motivation and encouragement to live their future lives with dignity and pride.

After the three hour ceremony the graduates and their families were pampered for another few hours. This time sailing Sydney harbour aboard a luxury yacht kindly donated to the hospital specifically for the graduates, who worked hard in their healthcare over the years to reach this point.

TAKING THE REINS

Our ultimate goal in transition care is to enable the patient to take a greater ownership for the management of their own medical condition - in collaboration with their old and new medical teams.

Each patient will achieve a different level of success with the challenges surrounding transition.

It is therefore important to build the adolescent's confidence and show them that they can gradually become independent and responsible for their own medical needs.

Our ultimate goal in transition care is to enable the patient to take a greater ownership for the management of their own medical condition

For a few patients this is a great opportunity to finally take over the reins from mum or dad. For most however it may be a scary concept. As such, ongoing reassurance and encouragement is very important, from both the medical team and from the family.

TRANSITION CLINIC

Last year Sydney Children's Hospital introduced their first transition clinic where the haematology patients were reviewed by their paediatric team alongside their new adult team. Together the patients and the teams discussed and planned the individual's healthcare needs.

The adolescent slowly builds their self-confidence as they start to take on some new responsibilities, i.e. speaking for themselves in clinic review, asking the doctor/nurse the questions rather than mum or dad asking, troubleshooting problems themselves with the team and managing their own medications. This can begin as early as 13 or 14 years of age so as to facilitate a gradual process.

Of course we always encourage the patient's family to continue giving support, care and guidance regardless of age. At the same time it is hoped that when the young adult moves to their new hospital, they will be more able to manage their needs and are prepared for the challenges that a new hospital, new staff, new routines can bring along.

Kate Walton is Haemophilia Foundation Australia Youth Project Officer

CYCLING CHAMPION TOURS DOWNUNDER

Kate Walton

Alex Dowsett is a British professional cycling champion with severe haemophilia. He spoke to Kate Walton during his visit to Adelaide for the Tour Down Under

In January 2012 some members of the bleeding disorders community, staff members of the Haemophilia Centre and I had the opportunity to meet Alex Dowsett, a professional cyclist with the British Team Sky who was competing in the Tour Down Under in Adelaide. Alex has severe haemophilia A and generously spared some time to speak to us.

Alex talked to the group about life as an elite cyclist and spoke openly about his experiences growing up with haemophilia.

EARLY DAYS

As a child with haemophilia, Alex found trying to fit in quite challenging. A lot of sports at his school were contact sports, which he could not do and this was quite demoralising for him. Active birthday parties were also off-limits because parents were concerned that he might be injured.

Instead, Alex's mother encouraged him to swim to help with his haemophilia. He started swimming five times a week – and ironically, this put him in a good position for cycling later in life. He became very fit and built up muscles and his lung capacity. He also didn't have the ankle or knee injuries early in life that he might have with other sports, so his ankle and knee joints were preserved and in good shape when he needed them later when cycling. Although he avoided contact sports, Alex tried many other sports when he was growing up, including sailing, go karting, running and basketball. He started cycling when he was 9 years old.

COMPETITION CYCLING

The group was very interested to hear how Alex managed professional cycling at an elite level. When asked if he found haemophilia to be a hindrance when he was first trying to find his place within the Sky Team, Alex answered, "No. I always thought it was going to be a problem but everyone in my team has been more supportive and more forthcoming with it than I thought they would be." Alex said that everyone in cycling knows about his haemophilia, as it's not something he wants to hide.

Alex spoke to the group in detail about his training regime for competitions including his diet pre and post-race, how many hours he trains daily, his daily massage when on tour and how he intended to deal with the Australian heat. He also spoke about how he manages his treatment, saying that his doctors have asked him to treat more often during a race, with a half dose on the off day, to keep his levels high because of the high risk of bleeds - "The target is be above 10%" – but when he is training, he reverts to a normal treatment pattern of treating every other day.

There was a lot of curiosity about what happens with cycling accidents. Alex explained, "There's always factor VIII with the doctor in the team car so if I crash so badly that I can't carry on, they'll whack that straight into me on the side of the road and cart me off to hospital." In 2010 Alex broke his shoulder blade. "It was pretty horrible," he said, "but I was lucky that the hospital I went to was a haemophilia specialist hospital."

Top left and right: Alex Dowsett in the Tour Down Under; and on the podium for a competition prize.

Photos courtesy Alex Dowsett

LONDON OLYMPICS

Alex is in the bid for the 2012 London Olympic Team and said, "It's 50/50 whether I'll go. There are eight of us in the running for five places. I just have to show that I can race well and show I can do a good job and hopefully be selected. I could go as number six and warm up and then not race. If I don't get selected I will be disappointed but it won't be through lack of trying. I could do with it being in London in 2016 but I don't think that's going to come around again, so it's a big opportunity. "

During his time in Adelaide, Alex went to the beach, a winery and a backyard barbeque. When asked if there was one thing he really wanted to do, he said he just wanted to see a kangaroo.

Alex finished 124th overall in the Tour Down Under.

In March 2012, after his South Australian tour, Alex broke his elbow when he had a collision during a cycling race in Belgium. Alex is a national time trial champion and this was a serious setback for his hopes to qualify for the Olympic team but he is now back into full training and will be racing again mid June.

You can follow Alex's progress at www.facebook.com/alexdowsettofficial

Left, lower left: Alex Dowsett talks cycling with bleeding disorder community members and HTC staff in Adelaide

Photos: HFA

When asked if he found haemophilia to be a hindrance when he was first trying to find his place within the Sky Team, Alex answered, "No. I always thought it was going to be a problem but everyone in my team has been more supportive and more forthcoming with it than I thought they would be."

Penny McCarthy and Megan Walsh are Clinical Nurse Consultants at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

MANAGING BLEEDS AT COMPETITION OR ELITE LEVEL

Penny McCarthy and Megan Walsh

Fit, active and healthy people with haemophilia generally report less bleeds as their fitness and musculature protects their joints.

If you participate in sport at a competition or elite level, your Haemophilia Centre can work with you to customise your prophylaxis regime individually based on your bleeding history. During intense training periods or competitions your total factor usage need not increase; however, your regime can be altered to cover sporting or competition demands. For example, prophylaxis doses can administered daily in smaller amounts to maintain adequate factor levels. If you normally infuse 1500 IU (international units) of factor three times per week, for example, we may instead recommend 750 IU daily with a rest day once a week.

As always, if trauma or injury occurs, apply basic first aid and follow the RICE principles (Rest, Ice, Compression, Elevation). Seek appropriate medical management and make sure you have your treatment wallet card with you.

It is also important to remember recovery and rehabilitation time following an injury may be a little longer or slower than an athlete without a bleeding disorder.

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

INSPIRED? GO DO IT!

Abi Polus

Be inspired. It is definitely great to be inspired by Alex and all the athletes competing in the Olympics. It is well known that exercise can keep you strong, fit and healthy mentally and physically and can also help prevent bleeds.

Often, around the time of big sporting events, physios and doctors see the incidence of muscle and joint injuries increase as everybody watching the events decide that they too can lift that weight, swim that distance, run that fast, perform that gymnastic feat (well, they could do the splits at aged 12 so why not re-try now…).

HERE ARE SOME TIPS TO PREVENT INJURIES:

Be realistic: How long is it since you last performed what you hope to achieve? How long will it take you to achieve your dream? These athletes have spent years and years training, modifying their lifestyle and diet to get there; like them set a goal and then work out how to get there in stages, slowly increasing the activity safely until you get to where you want to be. This will prevent both likelihood of injury and burn out.

Be selective: Choose a sport that suits you. Number one is that you must enjoy it; no one wants to drag themselves to do and practise and perfect something that they hate. But take into account your own body and its capacity. Frequent ankle pain? Running is probably not for you. Love to run but ankles not happy? Deep water running is for you. Regular back pain? Choose a Pilates class for a fun and healing workout (although see your physio first). Cycling can be very beneficial to those with haemophilia but there are a multitude of activities out there to choose from.

Be creative: You do not have to follow strict rules of organised sport. Try no-touch team games such as organising an adult version of Auskick or touch rugby. If you have an injury or problem during a gym program you can still exercise your other limbs or do different activities. Try a new dance style or different activity if your regular one is aggravating symptoms.

Don't be a stranger to physio. If you are thinking about taking part in sport at an elite or competition level, or just want to try something new, it is strongly recommended that you visit your physiotherapist at the Haemophilia Centre and have a full musculo-skeletal assessment first. This involves looking at the current range of movement and strength of your muscles and joints. If any specific problems show up, such as pain, weakness in muscles or target joints, your physio can give you an exercise program and advice on how to improve

these problem areas that are specific to you, and then and tailor it to your specific chosen sport, so that you can best perform your chosen activity. Remember, all Olympians have physiotherapy and medical advice both to prevent and treat any issues, in order that they achieve the best results that they possibly can.

It is definitely great to be inspired by Alex and all the athletes competing in the Olympics. It is well known that exercise can keep you strong, fit and healthy mentally and physically and can also help prevent bleeds.

FEATURED SPORT: CYCLING

*The information below is an adapted extract from **Boys will be boys** by Brendan Egan, Royal Children's Hospital, Melbourne, 2005. The publication helps people with bleeding disorders to be better informed about their sporting choices and understand the risks of different sports for them. Copies are available from your Haemophilia Centre or HFA.*

Participation
Cycling is a highly recommended sport for people with bleeding disorders. Participants are able to increase lower limb muscle strength without putting weight-bearing stresses through their joints. However, injuries are common.

Common injuries
Injuries from cycling are commonly caused by a fall, resulting in fractures and abrasions/lacerations. It is also important to be aware of head injuries as these may lead to serious complications in the person with a bleeding disorder. The remainder of the injuries are a result of overuse, particularly the knee, and occasionally the neck and back. "Saddle sores" are also common in cyclists.

Injury prevention
Warm up: a good general warm up may be to ride at a low intensity on a flat course, or to jog on the spot; stretches. If you start to get knee or any other pain see your physiotherapist as soon as possible.

PROTECTIVE EQUIPMENT

Mandatory: helmet

Strongly recommended: padded shorts with mountain biking

Optional: protective eyewear, padded bicycle shorts, cycling footwear.

This article has been published simultaneously with permission in *National Haemophilia* and *Bloodline*, volume 40, number 2, June 2012, the newsletter of the Haemophilia Foundation of New Zealand

Rebecca Cornwall is a New Zealand-trained occupational therapist and works in The Auckland Regional Pain Service (TARPS) at the Auckland District Health Board

Ian d'Young is the Haemophilia Physiotherapy Practitioner for the Auckland region and is the National Clinical Lead for Haemophilia Physiotherapy. Ian is co-chair of the Australia-New Zealand Haemophilia Physiotherapy Group

RETURNING TO WORK AFTER A BLEED

Rebecca Cornwall and Ian d'Young

TOP TIPS

- **Understand the role of rehabilitation**
- **Understand your physical limitations**
- **Calculate your tolerance for different activities**
- **Pace yourself - factor breaks into your day**
- **Plan to be flexible or structured**
- **Communicate with employers or co-workers**

Bleeding episodes into muscles and joints can be very painful. Once you have reported a bleed to your haemophilia centre or specialist physiotherapist, you may be advised to take some time off work to recover. You may also be advised to avoid certain activities, keep the weight off the limb or use a sling or pair of crutches. Getting you back to work again safely and in a timely manner after a bleed is important, and is a key role for physiotherapists and occupational therapists working with people with haemophilia. This article explores some 'top tips' that you may find useful when getting back to work.

WHAT TO CONSIDER

After the acute symptoms of the bleed (such as the pain, warmth and swelling) have subsided, your muscles may be weaker and your joints stiffer than before. As a result tasks that you were able to do with ease prior to the bleeding episode may now place you at a greater risk of having another bleed. So even when you are planning to return to work quickly after a bleed, there are important things that need to be considered in order to make your transition as smooth as possible.

When considering returning to work after a major bleeding episode, there are often dreaded barriers that spring to mind. Will I be able to manage physically? What rehabilitation do I need to do to get me back into shape? Will work trigger additional bleeds? What jobs can I do/manage? How can I manage fatigue or pain? What if I need time off? What will my employer say?

These are all very justifiable barriers when considering a return to work; however, it is possible to manage these well, take control and get yourself back to work quickly after a bleeding episode. It may help to work together with your nurse, physiotherapist or occupational therapist to make a plan. It is important to establish what is realistic and achievable for you at this present time, and what you need to know in order to prepare yourself for the demands of a work day in the future.

UNDERSTAND THE ROLE OF REHABILITATION

After the bleeding has settled, your body still needs help to reabsorb the blood from the joint or muscle, and you will need to exercise sensibly in order to restore the strength, flexibility and coordination to the affected site. Discuss with your physiotherapist the nature of your job, and the physical requirements of a normal working day. After considering the site of your bleeding episode or injury, your physiotherapist can help to develop an exercise program that is tailored to your individual needs. In most cases you will be set a 'home exercise program' to do several times each day. Remember, you are in charge of doing your program at home, so do not expect it to help if you are not doing your exercises!

UNDERSTANDING YOUR PHYSICAL LIMITATIONS

Take a step back. Think about the different tasks that you do each day at work. Reflect on your last working week before you had a bleed. What went well? What didn't go so well? What might you need to change when you go back to work? Are there things you could do differently? Are there certain tasks you have been told to avoid? Talking to an occupational therapist can be a really useful way

of identifying issues and solutions to assist you in getting back to work quickly and safely.

Think about simple things first, such as the amount of time you need to stand for at a time during a normal working day. Now compare this with your current standing tolerance. Will you need to arrange somewhere to sit for regular 'micro' breaks if your day normally involves standing for long periods? The same goes if you move heavy weights regularly. What weight can you lift repeatedly at work?

CALCULATING YOUR TOLERANCE

Your tolerance within an activity can be explained by the time that you can comfortably manage doing a task repeatedly, NOT the longest possible time you can complete an activity before stopping. For example, to work out your tolerance for sitting, you would sit down, start a timer and be mindful as to when you feel uncomfortable. For some people it is the time when fidgeting starts, for others when pain appears. For some it is only when they stand up that they recognize they have sat for too long. If you are one of these people you will need to trial different periods of sitting until you find a time where you remain comfortable on standing. Ensure you test yourself a few times at different times of the day or week or on different chairs to establish how long you can comfortably sit for. Following this make an average of these times and minus 25% - this ensures it's a time that you can currently manage.

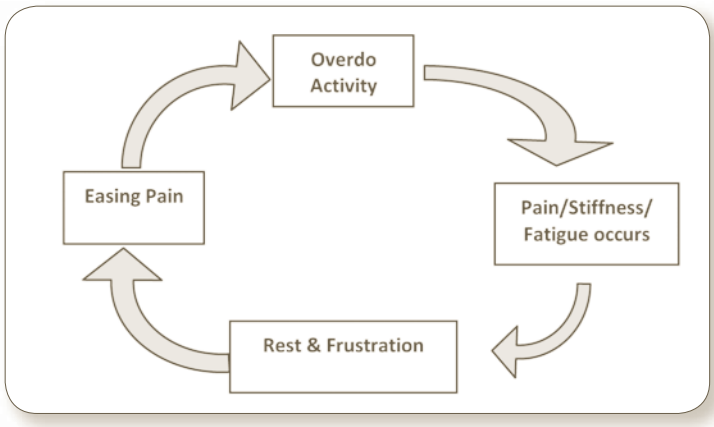
Once you have established your tolerance for different tasks using this technique, you can then determine when you need to take micro breaks throughout your working day. If, for example, your sitting tolerance is 20 minutes, this would mean you would factor breaks into your day every 20 minutes and gradually work to increase the time between breaks. Be mindful however to 'do no more on a good day and not much less on a bad day'. This technique can be applied to any of your tolerances you would like to increase such as standing, walking or typing.

PACING YOURSELF - FACTORING BREAKS INTO YOUR DAY

Breaks don't have to be obvious during your day. For example you could plan breaks by collecting the mail, going to the toilet, getting a drink, picking up photocopying or your next job sheet.

What is important is to plan out your day with respect to your physical/ mental tolerances. This will prevent the sort of 'boom and bust cycle' that is referred to in the diagram below. When you push yourself to your limits at work each day you may then experience heightened levels of pain, stiffness or fatigue, and as a consequence you 'bust' when you get home and find that the only activity you can manage is rest. This cycle can be frustrating and often repeats itself each day, limiting your ability to manage not just work, but other enjoyable, meaningful activities as well.

Short or 'micro' breaks are a good way of avoiding the 'boom and bust' cycle. Try to avoid being in one position or performing repetitive activities for too long. In the same way, think about how you can modify activities to distribute the 'load' more evenly or away from the site of your recent bleed or injury.



Boom and bust cycle

For example, if you have had a recent psoas bleed, then the recovering muscle will be placed under too much strain if you lean over a work bench while standing for long periods. Two ways of reducing the load to the muscle would be to avoid standing for periods longer than 20 minutes (for example, taking a short one minute rest sitting three times per hour) and placing a small step under one foot (this divides the load more easily between your back, psoas muscle and legs). Remember that your physiotherapist or occupational therapist will have lots of bright ideas on how to modify your work environment or change the way you work so that your body is able to recover. Make sure that if you do not have access to these services already that you ask your nurse specialist for a referral.

PLANNING TO BE FLEXIBLE OR STRUCTURED

It is important to examine your expected workload for each day or shift. Once you have an understanding of what is expected of you it can then be possible to juggle jobs to enable you to alternate tasks within your day. Here are a few questions you my ask yourself:

- Can you alter your start time, or number of hours?
- Is your present working schedule working for you?

- Can you maximize when you are at your best in terms of pain or fatigue and complete more difficult tasks then?

COMMUNICATING WITH EMPLOYERS OR CO-WORKERS

It is up to you whether you choose to let your co-workers know you have haemophilia. Often it can be helpful to discuss your condition with your employer and the impact that a bleeding episode may have on your work. Good communication will also make planning, modification of tasks or pacing a much easier process. You may also want to think about whether you choose to let one or more of you co-workers know about your condition. This can help them to understand why you may have a reduced a workload those days following a bleed.

RELAXATION

Relaxation can be a useful tool in managing tension, stress, fatigue and pain before, during and after work. Simply taking a step back from your work environment, then taking three deep breaths can be a good start. Notice any changes that occur following these breaths.

A number of examples of relaxation and meditation techniques can be found on this website

http://flexiblelearning.auckland.ac.nz/calm/18.html.

HAEMOPHILIA AWARENESS WEEK

Achieving your dream

Haemophilia Awareness Week
7–13 October 2012

Haemophilia Awareness Week is an opportunity for haemophilia foundations and other organisations, as well as individuals and families to take part in a campaign and activities to raise awareness about haemophilia and related inherited bleeding disorders throughout Australia. This year, the week of 7-13 October has been set aside and we encourage all our supporters to participate. The theme this year is "***Achieving your dreams***".

There are many ways you can help us promote Haemophilia Awareness Week:

- Take part in **Red Cake Day**
- set up a stand in your workplace, school, hospital or library
- hand out promotional items in your local area
- assist your local haemophilia foundation during the week
- organise a casual clothes day at your workplace or school
- organise a luncheon, sausage sizzle or morning/afternoon tea

Promotional items such as stickers, tattoos, slap bands, posters, and colouring-in sheets are available for schools, work places, hospitals and community centres. To place an order for items (free of charge), download an order form from our website www.haemophilia.org.au (click on the Awareness Week logo on our homepage to be directed or look under Events and Awards) or email hfaust@haemophilia.org.au. Please note that stocks are limited.

For further information about Haemophilia Awareness Week or to order promotional items, please contact the HFA office 03 9885 7800 or email hfaust@haemophilia.org.au.

RED CAKES CAN CHANGE LIVES!

It's true. They can. That's why HFA is calling on our friends and supporters to help us celebrate Haemophilia Awareness Week by taking part in our inaugural **Red Cake Day**!

It's easy…all you have to do is bake some delicious red cakes or cupcakes, decorate them, and share them with your friends or work colleagues in exchange for a donation or a gold coin.

You could take them to work, school, have a cake stall or simply host an afternoon tea with your nearest and dearest family and friends. Not only will you be having a delicious morning tea but you'll be helping raise funds and spread the word about haemophilia and other inherited bleeding disorders!

Then, simply send the donations to Haemophilia Foundation Australia. All funds raised will go to a range of programs and services ran around the nation.

Want your cakes to look extra special? Why not order some of our specially made H logo cupcake transfers? They're fully edible and will turn your red cupcakes into something truly fabulous! Check out the order form for more information. But hurry, we only have a limited number available!

Download an order form from our website www.haemophilia.org.au (click on the Awareness Week logo on our homepage to be directed or look under Events and Awards) or email hfaust@haemophilia.org.au.

CALENDAR

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

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

World Haemophilia Day
17 April 2013
www.wfh.org

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

CHI Study update

WWW.CHISTUDY.ORG.AU

The CHI (Charting Health Impacts) study is an online research study about the impact of hepatitis C on peoples' lives, both currently and in the past. The research study is being conducted by the Australian Research Centre in Sex, Health and Society, Latrobe University, Melbourne (ARCSHS). Due to funding and recruitment issues, the study has been suspended temporarily.

CORRECTION: The photos of Chris Gordon in the article "Achieving a Dream" on page 19 of *National Haemophilia*, No. 177, March 2012, were supplied by the AFL (Australian Football League) and published with permission.