

National



Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 187, September 2014

HAEMOPHILIA AWARENESS WEEK RED CAKES CAN CHANGE LIVES!



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BUDDY AWARDS

DO YOU KNOW SOMEONE WHO IS A GOOD BUDDY TO A PERSON LIVING WITH A BLEEDING DISORDER?



As part of the work to increase awareness of the challenges faced by people living with bleeding disorders, the Haemophilia Foundation Australia and Haemophilia Foundation New Zealand have launched the Buddy Awards, which are sponsored by Novo Nordisk.

The Buddy Awards recognise the significant medical, emotional and practical support provided by family, friends, healthcare professionals, teachers and others, to people with bleeding disorders.

The lack of public awareness of such disorders means that families and friends take on a great deal of responsibility for their sibling/friend and this often goes unnoticed. The Buddy Awards celebrate the

DO YOU THINK THEY DESERVE RECOGNITION? THEN NOMINATE THEM FOR A BUDDY AWARD TODAY!

invaluable contribution they make while also drawing public attention to the challenges faced by this vulnerable group.

Download your nomination form
<http://tinyurl.com/buddyawards2014>

Completed nomination forms should be submitted via email or post:

E-mail: buddyawards@cube.com.au
Post: Buddy Awards, c/o Cube,
PO Box 162, Rosebery NSW 1445

Nomination deadline
Nominations close **30 September 2014** so be sure to nominate your Buddy today!

Gavin Finkelstein is President, Haemophilia Foundation Australia



FROM THE PRESIDENT

Gavin Finkelstein

If any of us thought there would be time to slow down a bit after the WFH 2014 World Congress in Melbourne, we were wrong! Perhaps generated by the energy created by the Congress, HFA is working through a very full agenda of work at present, some of which I have outlined below.

GOVERNMENT FUNDING

Like several of our State/Territory Haemophilia member Foundations HFA has been working on government funding submissions and agreements. HFA has established an agreement with the Department of Health on agreed goals. Some of this funding is for education and communication through our website and *National Haemophilia*, some for our policy research and submissions and some for the work we do to support excellence in haemophilia nursing, social work and physiotherapy which is important for comprehensive care services at haemophilia centres.

MYABDR

HFA is also looking at ways we can contribute to a better understanding of the health outcomes of the care and treatment provided to our community. The Australian Bleeding Disorders Registry (ABDR) and MyABDR are important cogs in the wheels for helping to generate the evidence needed to justify the effectiveness of high expenditure on treatment products.

We encourage your participation in MyABDR.

We need to demonstrate what we know – that appropriate treatment and care, clotting factor as prophylaxis or on demand plus other

interventions such as physiotherapy, effective pain management and other services help us live our lives as independently and successfully as possible – less time off work and school, better joint health etc – but today it is not enough just to say this, evidence is needed. HFA encourages local research on this, so everyone can access the most suitable treatment to enable them live productive lives. MyABDR is an important tool to help people with bleeding disorders and their doctors and other treating health professionals understand better the impact of managing bleeds and treatment. It also generates aggregated data to support best practice. We will also be pursuing ways that people can access longer acting clotting factors for their treatment which we believe will also be a critical part of best practice.

HEPATITIS C

Another treatment issue of great concern is for people living with long term hepatitis C. We have made submissions to governments about the financial difficulties faced by individuals and their families due to the complications of living with hepatitis C and a bleeding disorder. We are increasingly concerned about our members who tell us they have delayed hepatitis C treatment or that earlier treatments were not successful. Some people have been waiting for new drugs with fewer side effects and higher response rates, with shorter treatment periods in some cases. We were very excited when two new drugs were registered for use in Australia recently, but very disappointed that a drug that might be successful in our community will not be funded by the government. Some of our

members with advancing liver disease are worried that time is running out for them to find a cure for their hepatitis C. HFA is getting further specialist advice about the potential of these drugs for some people in our community and has sought the assistance of the Australian Haemophilia Centre Director's Organisation (AHCDO) for advice and firm data.

HFA COUNCIL

Important governance work with our State/Territory member Foundations has led to several proposed amendments to the HFA Constitution for consideration at the upcoming Annual General Meeting in October. These changes are being considered because we want the HFA Council to be more agile and inclusive, and for decision-making to be more timely and responsive to the needs of our members.

FUNDRAISING

Our fundraising staff are working hard to seek funding from philanthropic trusts for funding for core activities of HFA and a range of projects including family camps for children and adults, peer support activities, and other special projects to support and educate youth, women and girls, and people who are ageing.

I look forward to keeping in touch on these important issues. ■

This article is adapted from the article in *Factor Matters*, the newsletter of Haemophilia Foundation NSW, March 2014 and is reprinted with permission.

Lyn Wong is a member of Haemophilia Foundation NSW



WHAT IS CAMP ALL ABOUT?

Lyn Wong

HFA supports a range of community programs and services across Australia. These programs include family and youth camps, mentoring programs, boys' day out and men's and women's peer support groups. They are supported by donations from individual donors, business, service clubs, and philanthropic trusts and foundations.

For more information, visit the HFA web site www.haemophilia.org.au or call HFA on 1800 807 173.

This story by Lyn Wong describes her son Jayden's time at the HFNSW Camp in November last year. It is a great example of how important camps can be for families, as an experience, for the fun and adventure and the peer support.

Camps for children living with an incurable life-long disorder can mean so much to them on so many levels, physically, mentally and emotionally. When living with a rare disorder like haemophilia, isolation and despair can often take over their lives, as it's difficult for them to associate themselves with others 'just like them' in the school or general public environment. In 99% of cases, they are the 'only one' with haemophilia at school, at a park, or at a party. For them, seeing other kids without haemophilia, doing all the 'normal' play activities without the side effects that they endure, can sometimes leave them feeling upset and wondering 'why me?', especially when they end up limping, in pain or requiring blood clotting medications after an outdoor activity.

This is why it is vital to have on-going support through the opportunities that the annual Haemophilia Camp can offer to our children, as well as their siblings, parents and caregivers. It gives them a place of 'belonging', knowing that they won't be the only child in pain, or cannot climb as high due to weak joints, and that regular factor infusions is the norm of every haemophilia family. Children with haemophilia do feel more connected with their fellow friends with the same condition.

The understanding amongst our 'Haemophilia Family' makes a huge difference to each of us.

A perfect example was when my son Jayden started feeling very sore in his legs by lunchtime on Saturday at camp. He needed to take a break and rest his legs. His haemophilia buddy, also named Jayden, felt the same way too. They both had sore legs and both needed a rest. That was all it took to make him feel so not alone! Jayden said "Finally, I have someone else that has sore legs like me, and we can take a rest together! I don't have to sit all by myself while others continue playing. Yay, I'm not the only one!"

GROWING UP WITH HAEMOPHILIA AND INHIBITORS

Jayden, now aged 10, was born with severe haemophilia A. His condition was discovered shortly after his birth when he suffered two brain haemorrhages. Soon after, Jayden's haematologist discovered he had developed inhibitors, or antibodies, to clotting factor treatment which made his treatment less effective.

Jayden has had numerous bleeding episodes in both his legs throughout his childhood. He currently undergoes daily injections, monthly blood tests, regular clinic appointments, weekly physiotherapy and hydrotherapy as well as weekly outpatient medical

appointments to manage his condition. He has lost much of the strength in his legs and sometimes has to use a wheelchair when he is having a bleed and during each recovery and rehabilitation phase.

In spite of this, I try to make sure Jayden lives as normal a life as he can, by taking part in as many activities as possible, including swimming, non-contact karate and, of course, camp. Having inhibitors means Jayden is a bit more restricted in what he can do, compared to other children with bleeding disorders.

A MORALE BOOST

This year Jayden participated a lot more than he did at previous camps. Since the removal of his central venous line in 2012, he gained the freedom to swim and from there, he progressed to more active sports that helped boost his confidence and overall fitness. His self-esteem improved and his increased participation in camp activities made this year's event a huge success. The extra entertainment such as the Reptile Walkabout Show, the Magic Show, and Children's Movie Night provided even more fun for kids of all ages.

Jayden also found Venipuncture Training very helpful in combatting his fears of self-infusion by watching the teenage boys with haemophilia demonstrating how venipuncture is done on yourself, without the need of a parent to manage their medical routine. He knew that if he started to do his own infusions, it would give him a sense of independence; hence, he is now more determined to try harder to fight his fears of needles.

The highlight of camp was definitely rock climbing, archery, laser wars and indoor ball games, all of which he thoroughly enjoyed.

Coming to camp this year has lifted his morale and hopes for a more positive future living with haemophilia. ■

Janine Furmedge is the Haemophilia Nurse Coordinator at the Royal Children's Hospital, Melbourne

GIVING FACTOR TO CHILDREN AT HOME

Janine Furmedge

Prophylaxis with factor concentrates has been, without doubt, a great advance in the management of severe haemophilia and is well established in developed countries such as Australia. However starting regular factor infusions in infants and young children brings many challenges; finding veins is often difficult and upsetting for all involved and the thought of home treatment is a daunting prospect for most parents.

Infusaports (or 'ports') are temporary devices that are surgically implanted to allow easy access to a central vein. Ports have a reservoir that is inserted under the skin, usually on the chest. The reservoir connects to tubing (a catheter) that is tunnelled under the skin and feeds into a large vein in the neck. A special needle is inserted through the skin and into the port reservoir and the injected factor travels along the catheter and into the bloodstream.

By establishing reliable vein access, ports make home treatment feasible in small children. But while ports bring considerable benefits, they are not without risk. Infection is the most common complication and parents are provided with comprehensive education so they learn how to administer factor safely and with a technique that minimises the risk of infection. Parents make a decision with the staff at their Haemophilia Centre if and when a port is appropriate for their child. And for children who have a port, the next step is to transition to peripheral veins once the veins further develop

The Haemophilia Centre at The Royal Children's Hospital Melbourne wanted to develop a formal port education package. As the first

step in the process we carried out a study to explore the experiences and education needs of parents who had learnt to use a port to administer factor to their child.

So what is it like for families learning to use their child's port?

Firstly, most parents were learning to use the port at a time when they were still dealing with the distress of the diagnosis of haemophilia in their child as well as beginning to experience bleeds, trips to the emergency department and treatment. So a very difficult time!

There were four main themes that emerged from the study focus groups:

1. Dealing with fear and anxiety

Most parents told us they were very anxious when accessing their child's port for the first time. They described 'shaking', 'sweating' and feeling 'nervous'. Many felt very emotional about putting a needle into their child and fearful of hurting them. There was enormous anticipation leading up to the first time they accessed their child's port but once it was over there was great relief and the feeling that in fact it wasn't so bad and much easier than expected.

2. A supportive learning environment

Many parents described the relationship with and the support received from the person teaching port access as one of the most important aspects during their learning. It was important that the

teacher could foster confidence in parents during this difficult time and that both parent and child felt comfortable with and had trust in their teacher. Respecting the needs and wishes of the child was significant, as by 'making my child feel comfortable you [the parent] are automatically in a different place'.

3. Establishing a ritual

Interestingly, many parents described the importance of having a routine or ritual around how the port was accessed. This helped both parent and child to feel comfortable and confident about the procedure. Children responded well to having some control and the ritual also assisted parents in their learning process. Parents described practices such as their child always sitting in the same place and position, always inserting the needle on the count of three and always setting out equipment in the same way.

4. Empowerment and liberation

Parents described taking over their child's treatment as empowering. After a life dominated by the uncertainty of bleeding episodes and urgent visits to the Emergency Department for treatment parents could now take control; 'feeling in control after feeling so out of control ... I think that's the biggest stand out about ports'. Ports were seen as a 'blessing', allowing most children to participate in all kinds of activities including sports and school camp.


What information did parents want in an education package?

Parents asked that a teaching package incorporate photos, checklists and 'step by step' instructions. They also expressed the desire to hear the voices and experiences of other families and so we included stories, anecdotes and tips from other parents. In addition, consistency of teaching was identified as very important and so a checklist and information directed to nurse teachers was included as a mechanism to address this issue,

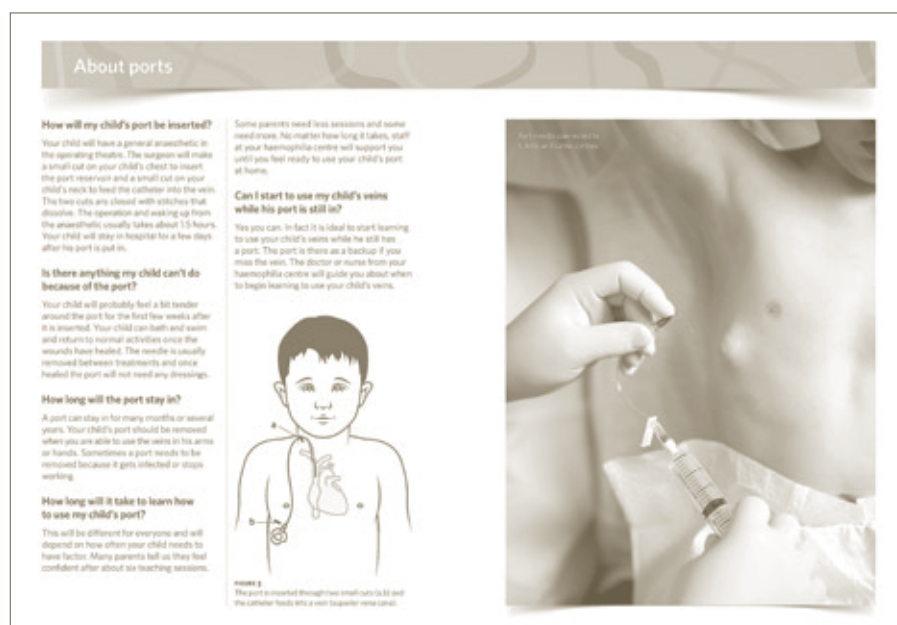
especially when several nurses are involved in the teaching process. The education package was developed with the help of parents who were experts in their child's port access as well as those who were learning for the first time.

The study helped us to have a greater understanding of what it is like for parents learning to give factor to their child via a port and to develop an education package that we hope will address parents' needs. The ability to give treatment at home was liberating for families but also meant less connection to the hospital and other families. Parents told us the enormous value they found in sharing their experiences and stories. This highlights the importance and great work of our Haemophilia Foundations in providing strong support and opportunity for children, families and adults with bleeding disorders to connect with each other.

More information

If you have any questions about your child and ports, please contact your Haemophilia Treatment Centre. 

Children responded well to having some control and the ritual also assisted parents in their learning process



RCH, Melbourne

ACKNOWLEDGEMENTS

A special thank you to the families who generously gave their time to share their experiences of learning how to use their child's port, to write their stories, to be photographed and to review and pilot the port guide. Development and publication of the port guide was supported by a Bayer Haemophilia Caregiver Award. Thank you also to the Educational Resource Centre at the Royal Children's Hospital, Melbourne for their expert photography and design.

PROF KEVIN RICKARD WFH AWARD

It was with great pleasure that we saw Professor Kevin Rickard awarded the WFH International Health Care Volunteer Award at the WFH Congress in 2014.

This award honours a health professional who "has contributed significantly in furthering the mission and goals of the WFH in a volunteer role."

Prof. Rickard began his career in haematology at St Vincent's Hospital, Melbourne, in 1960, and then took up haematology roles at Prince Henry and Prince of Wales hospitals in Sydney. Later he went overseas, studying at the Royal Postgraduate Medical School in London and then as a Fellow in Haematology at St Elisabeth's Hospital and Tufts University in Boston, Mass. USA.

He returned to Australia to an appointment at Royal Prince Alfred Hospital, Sydney, in late 1970 as Staff Specialist in Haematology, with responsibility for haemophilia care at the Hospital.

In 1986 Prof. Rickard founded the Haemophilia Centre, RPAH, Sydney.

This Centre was the result of many years of advocacy, supported by the Haemophilia Society of NSW, to convince the NSW Health Department and hospital administration of the necessity of a comprehensive care centre. This Centre remains the focus of adult haemophilia care in NSW and is recognised worldwide as a World Federation of Haemophilia International Training Centre.

Prof. Rickard was also committed to advancing treatment products and their supply in Australia. Over many years he advocated for improved blood products to treat haemophilia and sufficient clotting factor concentrate to meet all Australian patients' needs.

As well as his role at the Haemophilia Centre, Prof. Rickard has shown outstanding clinical leadership both in Australia and internationally. He was Chair of the Haemophilia Foundation Australia Medical Advisory Panel (now Australian Haemophilia Centre Directors' Organisation), Chair of the International Haemophilia Training Centres and Vice President,



Prof. Kevin Rickard receiving the Award from Alain Weill, WFH President
Photo: WFH

Developing World of the World Federation of Haemophilia. In the latter capacity he organised a number of teaching workshops on haemophilia in virtually every country in South-east Asia and co-ordinated training Fellowships more than 200 international trainees of the WFH. At Sydney University he became Clinical Associate Professor of Medicine in 1992. In addition to these roles, Kevin has contributed to many publications, sharing his professional knowledge and experience. In 1994 he was also the inaugural recipient of the Ron Sawers award for service to the Australian haemophilia community.

Prof. Rickard continues his support for the bleeding disorders community as patron of Haemophilia Foundation NSW.

We are delighted to see his contributions recognised in this important international Award. ■

SOURCE:

Bedbrook, P. A tribute to Kevin Rickard. National Haemophilia March 1994;83:3-8.

LIVING WITH VWD

SUSIE'S STORY

Hindsight is 20/20 or so they say...

I keep learning new things in my journey with a bleeding disorder and I've come to the opinion that this is actually OK. Up until the diagnosis of my second son with type 3 (severe) von Willebrand disorder (VWD), I had no idea I had a bleeding disorder. I was one of those statistics - a woman with symptoms but no diagnosis and so inadequate treatment. Fast forward to now: I have gained knowledge and perspective and I am being well treated by my Haemophilia Treatment Centre (HTC).

I have type 1 von Willebrand disorder, which is often explained as a mild condition which does not impact heavily on most people's lives. But everyone's experience is different. Growing up I was prone to bruising and bled freely. However, my mother maintained that our family were fast healers so it was OK. I remember hearing, "oh we just bruise, that's what we do". As a child I was not a generally healthy person and I think the idea of investigating the bruising was far from my parents' minds; they were just getting on with raising a family and dealing with my other illnesses. As I grew older and became more responsible for my own health, I worked through diagnoses of coeliac disease and a degenerative eye condition that needed major surgery. However, at no point was I having discussions about my bleeding, my bruising or my periods.

When my period started, my mother thought I would come to her with issues. However, as with many teenage girls, I already had a remote and challenging relationship with her. I also

had no perspective to indicate what was "normal". How do you know what to talk about when you have no terms of reference? How do you know what to ask about, when no-one else at home is having "those" discussions? So I muddled through with the information printed on packets and boxes and in the few girls' and women's magazines I came across. My older sister and I were in our own worlds at the time; we were very closed off from each other. Having children and the VWD diagnosis has actually brought us closer together. We can talk so easily now about experiences, past and current. This is what I wish for all women.

When my first son was born by caesarian, I had a postpartum bleed. I had lost consciousness, had 5 units of blood transfused and was taken back to theatre to resolve the bleeding. The experience was so harrowing I don't normally tell pregnant first time mothers my birth experience. And that 20/20 hindsight - my factor VIII levels were tested after my transfusion.... It begs the question what they thought they would find to explain the haemorrhage. And given VWF levels raise during pregnancy, it would have been prudent to test me 6 to 8 weeks after the birth. This was not done and there were no discussions with any health professional about my experience or the possibility of having a bleeding disorder. When my second son's birth was planned as a scheduled caesarian I had a fantastic care plan with preparations in the event of a bleed. After a lightning fast delivery and post operative care, I had no postpartum bleeding of issue. I thought I had

drawn a line under that awful event and it was a distant memory.

However when my son was diagnosed with type 3 von Willebrand disorder, this led to the testing and diagnosis of both my partner and me. Initially I was shocked, but the more I read about the condition, the more the pieces of the puzzle fell into place. The massive swellings on my legs the size of my fist I got with mosquito bites. The flooding and the massive clots passed with my periods. The time I grazed the back of my foot going down stairs and it bleed for hours, prompting a hospital trip for care. The oozing bleeding after routine dental visits. The countless other times I noticed, "Oh, I'm still bleeding, like it's just oozing..." I have always wondered if I inherited VWD or I was the first mutation in the family. I don't know if I am the only one in my family who has VWD.

So now, I engage with my health care professionals from a position of knowledge. My employer knows about my condition - this was helpful when I fell down the stairs at work and needed hospital care. I can manage my bleeding for dental work properly. I can manage my abnormal menstrual bleeding with good results. I can plan elective surgery with the involvement of the HTC to minimise issues. This has all been a direct result of my diagnosis. I've learnt that tranexamic acid is a regular part of my care. It's great for mid-cycle and heavy bleeding. It's also a minimum requirement for my dental visits. I've even had 6 teeth removed through the HTC with DDAVP as a pre-treatment for



bleeding. Whilst I did bleed I was confident I was receiving quality care where my whole health was being considered.

So, whilst I don't have daughters, I can share my story and appeal to women to share theirs, talk to their daughters, keep the lines of communication open. Build the skills to talk about what's uncomfortable; you never know how much listening may help to make a difference. And if you're working through a diagnosis, information is power. Sift through as much information as you can, read the research that is coming out. Learn about the different types of conditions and how they impact on treatment options. Attend the events held by your local Haemophilia Foundation for women. If there aren't any, get some started. Ensure your local Foundation is inclusive. Go to the conferences and camps for people with bleeding disorders,

be a part of the community – it's diverse and supportive. Being a part of something bigger than yourself is a fabulous way to gain perspective and new strategies for treatment. Become informed so you can be an active participant in your care.

And share your story. Listen to the stories of others. We can all learn so much. ■

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.

SOURCE:

Haemophilia Foundation Australia. A guide for people living with von Willebrand disorder. Melbourne: HFA, 2010.

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:

Coderouge program for women and girls (Canadian Hemophilia Society) <http://www.coderougewomen.ca>

Victory for Women (National Hemophilia Foundation, US) <http://www.victoryforwomen.org>

Von Willebrand disease (World Federation of Hemophilia) <http://www.wfh.org/en/page.aspx?pid=673> ■

HFA WOMEN AND GIRLS PROJECT

HFA is continuing with its work to develop information resources for women and teenage girls with bleeding disorders.

WOMEN'S RESOURCES

These will in a magazine style and will include the personal stories of women who have a bleeding disorder, including those who carry the haemophilia gene or have von Willebrand disorder (VWD).

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

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

There will be two new resources for women:

- Carrying the gene for haemophilia
- Living with a bleeding disorder.

HOW TO BE INVOLVED?

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

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

CARRYING THE HAEMOPHILIA GENE: SPECIAL ISSUES FOR GIRLS AND WOMEN

CLOTTING FACTOR LEVELS AND SYMPTOMS

Many girls or women who carry the gene causing haemophilia do not have signs or symptoms of a bleeding disorder. If at least one of their X chromosomes has a factor VIII or IX gene that works, their body can usually produce normal or near normal levels of factor and they do not have bleeding problems.

However, some girls or women who carry the haemophilia gene may have a bleeding tendency. Females are often described as "symptomatic carriers". If their factor levels fall in the range for mild haemophilia (5 – 40% of normal clotting factor), they may sometimes also be referred to as having "mild haemophilia".

Examples of having a bleeding tendency may include:

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

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

"Heavy periods aren't normal, and can make life pretty hard. It's OK (and even good!) to talk about it and share information with doctors and others, to find out more, to understand the options that you have, and to support others by sharing your story about being a carrier."



- 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, HFA Policy Research and Education Manager: socallaghan@haemophilia.org.au, or phone 1800 807 173 (Mon to Fri)

INFORMATION FOR YOUNG WOMEN AND TEENAGE GIRLS

Alongside the women's project, HFA has also started working on information resources for young women and teenage girls in the 13-25 age group.

The style and topics covered will be developed with young women and teenage girls with bleeding disorders, and parents and Haemophilia Centres will also be asked for input.

This project is being led by Hannah Opeskin, HFA Health Promotion Officer: hopeskin@haemophilia.org.au phone: 1800 807 173 (Mon, Tue, Fri) H



PARENTS

Do you have a daughter with a bleeding disorder aged 13-25 years?

HFA is currently developing new information resources for young women with bleeding disorders. These resources are for young women aged **13-25 years**.

As part of the development and evaluation process, HFA is looking for parents who have a daughter aged 13-25 years to help share ideas about content that they believe would be beneficial.

These resources are being developed in addition to the women's booklets.

If you are an Australian parent with a daughter aged 13-25 years, HFA would love to hear your ideas about topics and how it will be displayed. It will only require a small amount of your time to answer a survey and when you finish you will go into the draw to win an iTunes voucher!

All it takes is an email to Hannah Opeskin (Health Promotion Officer) to register your interest. E: Hopeskin@haemophilia.org.au



YOUNG WOMEN

Do you have a bleeding disorder?

Are you aged between 13-30 years?

Do you carry the gene – or think you might carry the gene - for a bleeding disorder?

HFA IS LOOKING FOR YOU!

HFA is currently developing new information resources for young women with bleeding disorders. These resources are for young women aged **13-25 years**.

HFA is looking for young women aged **under 30 years** with a bleeding disorder to help share their ideas about topics and what the resource should look like. (If you are aged 25-30 we want to hear your thoughts and ideas about information you wanted when you were younger!)

It will only require a small amount of your time to answer a survey and when you finish you will go into the draw to win an iTunes voucher!

All it takes is an email to Hannah Opeskin (Health Promotion Officer) to register your interest. E: Hopeskin@haemophilia.org.au

HEP C NEWS

Advancing liver disease and limited treatment options is a real problem for some of our community members with hepatitis C

Treatment that can cure their hepatitis C is a high priority

HFA welcomes the recommendation of the PBAC to add simeprevir (Olysio™) to the Pharmaceutical Benefits Scheme (PBS) for the treatment of genotype 1 chronic hepatitis C.

However, we were disappointed to see that the PBAC rejected sofosbuvir (Sovaldi™) for the treatment of genotypes 1 to 6 chronic hepatitis C on the basis of its high cost and limited information about cost-effectiveness.

Listing these new hepatitis C drugs on the PBS would mean the cost is subsidised by the Australian Government. The PBAC is the government Advisory Committee for the PBS.

Both drugs have already been approved by the Therapeutic Goods Administration for use in Australia. But without subsidies they are out of reach for most people with bleeding disorders and hepatitis C.

You may recall that HFA surveyed community members on these new treatments and made a submission to PBAC with their answers about the potential impact of these drugs on people with bleeding disorders and hepatitis C.

About sofosbuvir and simeprevir

Sofosbuvir and simeprevir are part of the new wave of direct acting anti-viral (DAA) hepatitis C drugs. In clinical trials they had very high success rates, few side-effects, and shorter treatment courses (eg, 12 or 24 weeks). They need to be taken in combination with other medications (eg, interferon, ribavirin, ledipasvir) to be effective. Professor Ed Gane from New Zealand explained more about these new DAAs at a recent conference in Brisbane – tinyurl.com/new-hep-c-treatments.

How safe and effective are these new treatments for people with bleeding disorders? Sofosbuvir has had encouraging results - in a small study in of people with bleeding disorders in New Zealand, it has been shown to be both safe and highly effective when it was combined with ribavirin and ledipasvir, including for people who have previously had unsuccessful treatment¹.

Next steps

Advancing liver disease and limited treatment options is a real problem for some of our community members with hepatitis C. Treatment that can cure their hepatitis C is a high priority.

HFA will be following up with more representation to government on these new treatments. The first step is to arm ourselves with some more detailed information about the potential benefits of these treatments for our community members in particular, and we will speak to hepatitis specialists about this. We have also asked the Australian Haemophilia Centre Directors' Organisation (AHCDO) for their advice and help with understanding the situation for people with bleeding disorders and hepatitis C nationally. This involves clarifying the data and producing a report that does not identify individuals but gives solid evidence of the reality for our community members. ■

REFERENCES

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

WORLD HEPATITIS DAY

World Hepatitis Day was marked internationally on 28 July 2014.

This year the focus was on checking your liver health regularly – simple, easy... and it could save your life!

Checking your liver health regularly is particularly important for people with bleeding disorders and chronic hepatitis C.

But it is equally important for everyone, whether you have hep C or not, to take care of your liver health generally.

The Love Your Liver web site (www.loveyourliver.com.au) gives tips on looking after your liver, delicious liver-friendly recipes, information about your liver and how it works, and the latest research on liver health.

HFA is committed to improving liver health and reducing hepatitis C stigma and discrimination in Australia. We worked together on the national campaign with Hepatitis Australia – you may have seen some of our Facebook posts and tweets! And with the State and Territory Foundations, we made sure the Liver Health Check fact sheet and poster reached our members through our newsletter mailouts, along with information on our web sites and social media postings.

More information is available at www.hepatitisaustralia.com. #

Don't wait for warning signs

LIVER CHECK NEEDED

If you're living with HEPATITIS B or C (or think you may be), talk to your doctor about a regular LIVER CHECK-UP. It's easy and it could save your life.

WORLD HEPATITIS DAY

hepatitis australia National infoline: 1300 437 222
www.facebook.com/loveyourliver.com.au www.twitter.com/love_your_liver www.loveyourliver.com.au

LOVE YOUR LIVER
www.loveyourliver.com.au

SA

Sharon Caris is Executive Director, Haemophilia Foundation Australia

SOUTH AUSTRALIA UPDATE

Sharon Caris

It was great that so many South Australians were able to attend the 2014 World Congress in Melbourne in May.

Several of those people said they would like to keep connected with one another and we hope they will do so informally. We are also exploring having an activity late in 2014 in Adelaide for people to get together. At this stage we are not sure of the form this will take but we are currently speaking with community members and health professionals about what they think would work best. We are thinking of a one day activity at the weekend that might be suitable for people with bleeding disorders of all of all ages, and their family members.

Please let Sharon Caris know if you have any ideas - scaris@haemophilia.org.au #

AIDS 2014

Suzanne O'Callaghan

AIDS 2014, the International AIDS Conference, was held in Melbourne in July 2014 – and with nearly 14,000 delegates from all parts of the world was a massive international meeting. I was grateful to receive a scholarship from the Australian Government to attend this extraordinary event. What a great opportunity to hear the latest information on HIV and meet with HIV workers and organisations from Australia and around the world!

It began on a very sombre note with the news that a number of very well-known delegates had lost their lives on flight MH17 on their way to the AIDS Conference. The tributes to the delegates highlighted the determination of all to continue their work, and the Conference went on, very motivated to achieve its goal of stepping up the pace to end the HIV epidemic.

HIV/HCV Co-infection Satellite Meeting

This meeting was held in the two days prior to the AIDS Conference and focused on the new range of Direct Acting Antiviral (DAA) hepatitis C treatments that are beginning to go through approval processes internationally.

It was particularly interesting to hear that hepatitis specialists are more confident that these new treatments will be safe and effective for people with HIV/HCV co-infection. One presentation noted that, after the European approval of new DAAs for use in chronic hepatitis C, the European Association for Study of the Liver (EASL) Guidelines now recommend treating HIV/HCV co-infection the same as HCV mono-infection, with some attention to potential HIV antiviral drug interactions. HIV drug interaction clinical trials with each of the new DAAs will be important to understand drug safety, but the recommendation now is that they are done earlier

so that they can be available at the time of approval, and are part of the decision-making about indications for treatment.

Honouring the past, hope for the future - Witness Seminar

As part of the Conference's work to understand the ongoing impact of HIV on the community, there are also several events to recognise and remember the experiences of people with HIV (PLHIV) in Australia, including people with bleeding disorders. One of these was the Witness Seminar, paying tribute to the Australian response to AIDS in the 1980s. Jenny Ross, who was HFA President at the time, took a leading role in the national response and attended the Seminar with Sharon Caris and myself. Dr Roger Garsia, a clinical immunologist from the Royal Prince Alfred Hospital in Sydney, also spoke about difficulties with discrimination during that period and his experiences with arranging blood sample testing for people with haemophilia – there was such



Colleagues lead a minute's silence for the delegates lost on MH17



Jenny Ross at the Witness Seminar

fear of transmission among the couriers that he drove the blood samples to the Reference Laboratory in Melbourne himself. It was an important and memorable reminder of the tremendous – and in many cases, lasting – impact on the bleeding disorders community.

Ageing

With the improvements in HIV treatments, people with HIV (PLHIV) in Australia are now living into their senior years. Several sessions dealt with issues of ageing and some interesting points were made:

- Long term studies show improved outcomes from treating HIV earlier – this reduces non-AIDS complications, which increase with ageing
- If the person's CD4 count is maintained above 500, survival is the same as for the non-HIV population
- Over 50, the effect of smoking on the cardiovascular system in PLHIV is increased
- Antiviral therapy toxicities contribute to the impact on comorbidities, particularly lifestyle diseases (diabetes, cardiovascular disease, etc)

One of the issues with growing older is that the person with HIV may need

supported accommodation in a residential aged care facility, like a hostel or nursing home. Research on this shows:

- Aged care facility staff want more education about how to care for PLHIV and preventing transmission – reminders about universal precautions are important.
- Make sure there are simple clear messages for health care workers – don't overwhelm them with complexity.
- It works better if PLHIV are trained to manage their health care workers and can teach them how to care for them.

Overall there was quite a celebration of ageing with HIV at the Conference, with an attractive photographic display inviting older delegates with HIV to participate. The importance of peer support was also acknowledged. One presenter noted that peer support can be very valuable in maintaining wellbeing, particularly if the peer is a similar age. A weekly phone call to touch base can make all the difference with depression. It was great to see some of the peer strategies already used by Haemophilia Foundations, such as "old boy" lunches and regular social contact, being validated in an international forum! ❏

MY AGED CARE

Since 1 July 2014 there have been important changes to the aged care system managed by the Australian Government. This covers residential aged care and support at home through a Home Care Package, and generally applies to those over 65 years of age.

Where to find more information?

Aged Care Assessment Teams (ACAT – also known as ACAS in Victoria) are available across Australia, to help the elderly and their carers determine what kind of care will best meet their needs if they are having difficulty managing at home without assistance.

The following are good reference guides for information about aged care services:

DPS Guide to Aged Care is available for each state and has extensive information. It is available at www.AgedCareGuide.com.au and hard copies are available from hospital social workers and Aged Care Assessment Teams.

Visit the **My Aged Care website** at www.myagedcare.gov.au or call 1800 200 422.

Operators are available to discuss aged care needs from Monday to Friday 8am to 8pm, and Saturday 10am to 2pm

Five steps to entry into an aged care home - available in booklet form from communications@dss.gov.au or at www.myagedcare.gov.au, or from a hospital social worker or Aged Care Assessment Team. ❏



Global Village: Male peer support - a Hawaiian PLHIV hula troupe

Suzanne O'Callaghan is Policy Research and Education Manager, Haemophilia Foundation Australia
Peter O'Halloran is Executive Director and Chief Information Officer and Lachlan Meng is a Support Officer at the National Blood Authority

MYABDR UPDATE



Suzanne O'Callaghan, Peter O'Halloran and Lachlan Meng

It hardly seems like any time since MyABDR was released - the end of February 2014, to be exact! - and yet there have already been two new releases with more features and enhancements, and another is due for release in early November.

You asked for it!

Enhancements for new releases are developed from feedback by:

- The MyABDR focus group (6-9 volunteers - a sample of people with bleeding disorders or parents from around Australia)
- Community members at MyABDR information sessions
- Haemophilia Centre staff
- MyABDR users survey responses
- Feedback provided directly by users to the MyABDR Support helpdesk.

So if you gave some feedback or made suggestions in the July 2014 MyABDR User Survey, said what you thought at a community session, phoned or emailed MyABDR Support with a problem or suggestion, your comments have been used to improve MyABDR.

'Bugs' (where something is not working as it should) are fixed straight away by the developers at the National Blood Authority (NBA). Other proposed improvements are checked at several levels and prioritised for new releases. In August 2014, for example, one of the tasks for the MyABDR focus group was to give their preference on some possible improvements for recording treatment and getting reports from MyABDR. This will then go to the Haemophilia Centre representatives at the ABDR User Reference Group to make sure it works for them too.

What's new?

The second and third releases in May and July 2014 included new features and fixes, for example:

- Upload photos when you record treatment or write a memo, along with the option to 'hide' this photo from the treatment centre (i.e. make it a personal note)
- The ability to upload a range of documents (such as PDFs, Word, Excel and images) through the MyABDR website.

Two further releases of MyABDR are scheduled over the coming six months to bring you further improvements and features. The next release (scheduled for early November) includes enhancements such as:

- Changes in the way that the synchronisation works, which will more than cut in half the amount of time the synchronisation takes and ensure that data is always captured in the central database, even if an error occurs on your smartphone
- A short-cut to your treatment plan from the home page of the screen – making it quicker and easier than ever before to get to this key information
- Changes in the way the 'copy forward' function works when recording treatments or entering received product to reduce the number of inadvertent double-entries experienced by some users.

Have you updated with the new release?

Make sure you update your smartphone with the latest version of the app to install the new features and fixes.

Finding out about new releases:

- You will receive an email alerting you to the new release
- Your smart phone will alert you when an update becomes available.

Then

- Go to the App Store (iPhone) or Google Play (Android)
- Search for MyABDR
- Check for UPDATES
- INSTALL the new release.

For a cleaner installation, you may prefer to uninstall the existing MyABDR app on your smartphone and replace it by installing the new version. *Make sure you go online to sync your data at the home page before you uninstall the app!*

If you use the web site, you don't need to do anything – you will just see the new features the next time you login. ■

NEED HELP? MEET THE MYABDR SUPPORT TEAM!

If you have problems with the MyABDR app or web site at any time of day or night, you can contact the MyABDR Support team – they are only too happy to help you!

They can:

- Walk you through how to use MyABDR
- Help with login and password issues
- Fix problems with your recorded entries
- Log bugs and other software problems, chase them up – and give you a call back to let you know the progress
- Take your suggestions for improvements.

"I needed to call the MyABDR Support team regarding a question I had - the friendly team answered my question, and gave a follow up call... great service!" said a user from NSW.

Developing additional ways to contact the Support team was one of the hot topics under consideration by the MyABDR User Reference Group during its August meeting and one that the Support team has taken seriously. "In early 2015, we will be implementing a live-chat through our website to make it easier than ever for MyABDR users to contact us for support", said Lachlan Meng.

Contact the MyABDR Support Team

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



The MyABDR Support team (left to right): Nathan, Jo, Petra, Lachlan, and Chris

BREAKING NEWS

In August 2014 MyABDR won merit commendations in two categories of the national iAwards – Government and Health.

The iAwards honours the best and most innovative solutions and inspirational companies and individuals in the ICT industry. 

YOUTH UPDATE

Hannah Opeskin



Although the World Congress has been and gone, life at HFA never slows. We are currently working on several ideas to ensure that our young people have access to the most up-to-date resources and that events are always happening in their local state.

Catch-ups

A youth catch-up was held in Hobart in July 2014 and received a large amount of support and enthusiasm. It was excellent to see both old and new faces come together for a casual movie night. A catch-up for Victoria is in the planning stage and should be underway soon. Young people across Australia are invited to organise and attend catch-ups in their own state.

Factored In

The Factored In website was created by young people affected by bleeding disorders for young people.

We are currently consulting with young people about the web site and distributing a youth survey so that we can obtain further feedback and make improvements. The web site improvements will include a software update to ensure it runs quickly and smoothly. A second level administration will also soon be developed, allowing youth leaders to update the website events with their catch-ups.

We are currently working on several ideas to ensure that our young people have access to the most up-to-date resources and that events are always happening in their local state.

Shortly, Factored In will have new content including transition, boy and girl stuff. As always, we encourage young people to contribute to the website and become a member to make sure they are kept updated with new content as it becomes available. The consultation and new improvements are aimed at increasing youth involvement.

Further training about youth mentoring and moderation for Factored In will also be further explored and developed. ■



YOUTH NEWS

HFA YOUTH LEADERS SPEAK UP

Sam

I feel that it is important for young people to speak up and have their voices heard at focus groups and other events because the youth bring brand new ideas that are desperately needed.

I believe that growing up with technology and being surrounded by it my whole life gave me insights and ideas the older attendees might not have thought of.

Hamish and Sam at the MyABDR focus group



Hamish

In September of 2008 I was given the opportunity to go on an HFA youth weekend/camp just outside of Adelaide on behalf of HFNSW. At the camp the HFA Youth Committee had their monthly meeting and I was asked if I wanted to join. This was the beginning of my time representing youth with haemophilia.

At the time I was a bit daunted by responsibilities that might come with the role, but I outgrew that. Since then, I have been asked to give a patient perspective of inhibitors and treatment as well as be part of a medical questionnaire panel, which gave me the opportunity to talk to other youth with bleeding disorders and their parents from around the country as well as New Zealand. I also attended the World Hemophilia Congress in Melbourne and answered questions about the HFA Youth Leadership training.

Over the last 6 years I have given voice to my opinions on behalf of young people so that others will want to step up be part of both their State Foundation and the national Foundation. Together we can continue to improve our lifestyle as people with bleeding disorders and have a place to share our experiences and make lasting friendships. **✦**



RED CAKE DAY



Red Cake Day during Haemophilia Awareness Week is around the corner.

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, von Willebrand disorder and related inherited bleeding disorders throughout Australia during the week of 12 - 18 October 2014.

HFA is calling on our friends and supporters to help us celebrate Haemophilia Awareness Week by taking part in Red Cake Day!

Last year we raised over \$15,000 from Red Cake Day activities and we

see this as a very simple fundraising opportunity that all our friends and supporters can easily participate in. Please help us.

It's easy to host a Red Cake Day during Haemophilia Awareness Week

- 1 Register your event and order promotional items online at www.haemophilia.org.au/redcakeday
- 2 Download a host kit
- 3 Invite family, friends, work colleagues to your event. You can use our invitation cards
- 4 Bake Red Cakes and host your event. We have a yummy Ruby Red Velvet Cake Recipe in the host kit

5 Thank the people that came to your day and donated. You can download a thank you card

6 Collect and bank your funds.

There are many things you can do –

- 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, posters, and colouring-in sheets are available. ❏

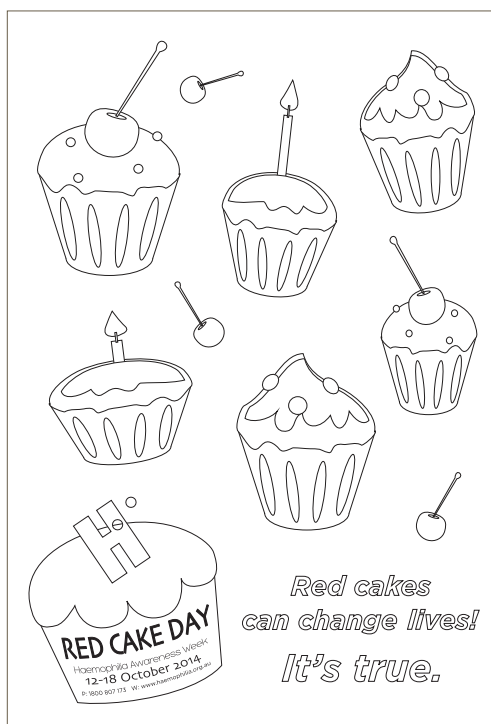
COLOURING IN COMPETITION

Once again we are running a Colouring In Competition. So get your school, local community group or friends involved – anyone can enter! Sheets can be downloaded online or ordered through the Red Cake Day website. There are 3 age categories –

Category 1:
children aged under 4 years

Category 2:
children aged 5 to 8 years

Category 3:
children aged 9 to 11 years ❏



FOR MORE INFORMATION AND TO ORDER PROMOTIONAL ITEMS:

- Visit the Red Cake Day website at www.haemophilia.org.au/redcakeday
- Or call Natasha at HFA on 1800 807 173
- Or email donate@haemophilia.org.au.

Help people with a bleeding disorder
Achieve Their Dream and support
Red Cake Day during
Haemophilia Awareness Week



***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

Red Cake Day!

Haemophilia Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations, to take part in a campaign and activities throughout Australia to raise awareness about haemophilia, von Willebrand disorder and related inherited bleeding disorders during the week of **12-18 October 2014**.

Promotional items will be 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 or email donate@haemophilia.org.au. Please note that stocks are limited.

For more information on Haemophilia Awareness Week and Red Cake Day visit

www.haemophilia.org.au/redcakeday or call HFA on 1800 807 173



Like HFA on Facebook

www.facebook.com/RedCakeDay



Follow HFA @[Haemophilia_Au](https://twitter.com/Haemophilia_Au) and join the conversation at

[#redcakedayhaemophilia](https://twitter.com/redcakedayhaemophilia)



HAEMOPHILIA FOUNDATION AUSTRALIA

CALENDAR

Haemophilia Awareness Week

12-18 October 2014

Tel 03 9885 7800

Fax 03 9885 1800

Email hfaust@haemophilia.org.au

www.haemophilia.org.au

World Haemophilia Day

17 April 2015

www.wfh.org/whd

17th Australian & New Zealand Conference on haemophilia & related bleeding disorders

1-3 October 2015

Gold Coast

Tel 03 9885 7800

Fax 03 9885 1800

Email hfaust@haemophilia.org.au

www.haemophilia.org.au

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



SAVE THE DATE!

17TH Australian & New Zealand Conference on haemophilia & related bleeding disorders

17th Australian & New Zealand Conference on haemophilia & related bleeding disorders

1 - 3 October 2015

Gold Coast

Tel 03 9885 7800

Fax 03 9885 1800

Email hfaust@haemophilia.org.au

www.haemophilia.org.au



1 - 3 OCTOBER 2015 • GOLD COAST



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