National Haemophilia
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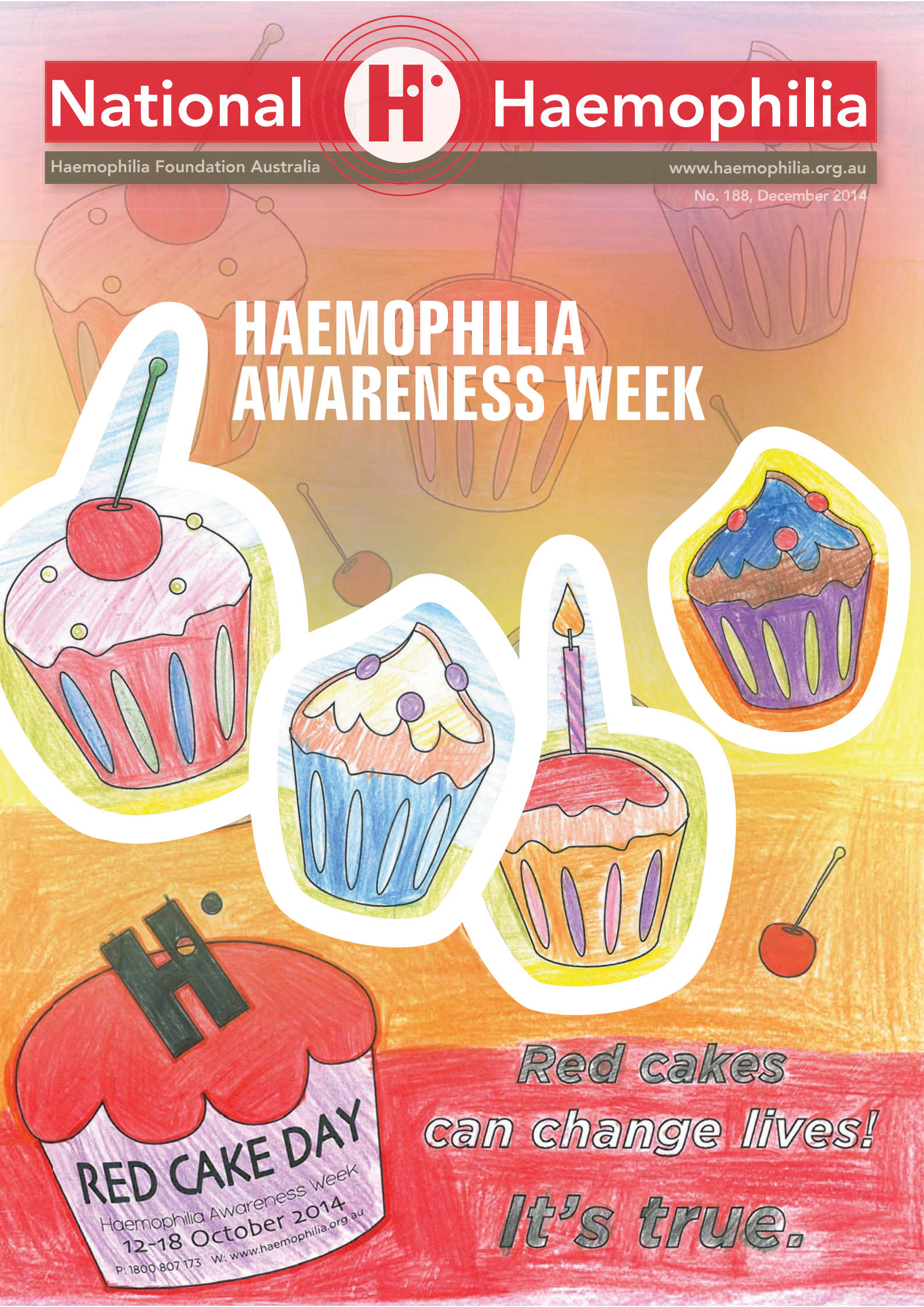
HAEMOPHILIA AWARENESS WEEK



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RED CAKE DAY

2014 HAEMOPHILIA AWARENESS WEEK

The artist with the 3D art at Customs House

Haemophilia Awareness Week and Red Cake Day was held this year from 12 to 18 October 2014. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about inherited bleeding disorders.

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

Just under 100 schools, hospitals, libraries, families and local communities around the country received promotional materials to help them run their own Red Cake Days and Haemophilia Awareness Week activities. They held different types of events, but they all worked together with us to raise awareness

Hamish and Jacob at Customs House

Biogen Idec Red Cake

about bleeding disorders or host a Red Cake Day. We are grateful for the support and uptake of this exciting event which we hope is becoming a regular feature on everyone's calendar.

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

An exciting Red Cake Day event at Customs House in Sydney was sponsored by Pfizer. With a wonderful 3D art piece of a Red Cake and cupcakes the day was a great success.

ALISON'S HAEMOPHILIA CHALLENGE

Alison Cameron has a 2 year old son Jasper with mild haemophilia.

"We found out last year after a bump on Jasper's head wouldn't stop bleeding. This caused his forehead to swell dramatically. He spent a week in hospital receiving daily infusions of factor to help his blood clot and stop any bleeding. It was a traumatic time, watching him undergo all the necessary medical procedure. Having no family history of this rare genetic disorder, it was a shock to find out he had haemophilia," said Alison.

Alison set up challenges to complete during Haemophilia Awareness week and raised money at the same time.

Said Alison,

"My challenges I set were –

If donations reach $150 I will dye my hair red (to reflect Red Cake Day, which is part of Haemophilia Awareness Week).

If donations reach $250, I will hold a mouse! If you know me, you'll know how much I HATE mice so this is a big deal for me! I usually scream when I just see a mouse!

If I raise $350, I will sing Karaoke in public! This scares me more than holding a mouse, probably because I am a terrible singer!

If I raise $500, I will get a tattoo of a cupcake to reflect Red Cake Day! I'm a wuss when it comes to pain! Plus this is permanent so I think it's worth it!

"I have just hit $1000 so have decided I will complete a high ropes course because I am afraid of heights so thought this is an appropriate personal challenge" Said Alison

"If my two year old son, Jasper, can bravely face all that he has been through then I can face a few of my fears in order to raise awareness of haemophilia, which has no cure. He will have it for life and possibly pass it on to his children."

Thank you to Alison and her supporters.

THE RED TRAIL

The RED Trail was a 7km walk in Sydney organized by Lyn and her son Jayden. Jayden is 11 years old with haemophilia. He is determined to not allow haemophilia to define his life. He wanted to create The RED Trail event to overcome the weakness in his legs from bleeds into his joints and challenge his ability to get back on his feet stronger than ever before.

Jayden reached the finishing line after completing the demanding 7km of the Iron Cove Bay walk together with his amazing team of supporters. Around $10,000 was raised. In his speech on the day, Jayden gave a powerful message to his supporters, "I'm here today to show you that you never give up, even if you have haemophilia."

PAINT THE TOWN RED

Neerim South & Bendigo Bank Branches, South Gippsland Region

Now in its sixth year, the township of Neerim South in Victoria once again hosted 'Paint the town Red'. The event is organised by Donna Field and a wonderful team at the Neerim District Community Bank®. We are grateful that staff at Bendigo Bank Branches in the South Gippsland Region also displayed posters and promotional items to raise awareness about bleeding disorders and helped to raise funds.

COLOURING IN COMPETITION

CONGRATULATIONS TO THE WINNERS:

4 and under
Mia, Paynesville VIC

5-8 years
Abbey, Geelong West VIC

9-11 years
Jessica, Drouin VIC

HAEMOPHILIA AWARENESS WEEK

THE BACK ROOM STORY

Jo Luciani, HFA Administration Assistant, has been instrumental in organising promotional resources for Haemophilia Awareness Week. She explains how it all works:

Haemophilia Awareness Week – and the lead up to it - is an exciting time to be around the HFA office.

Once Natashia has determined the promotional items HFA will have available, it is my job to count out, register, pack and send out the orders that our supporters need to embellish their fabulous events.

So, for an hour or so on each of my working days for a number of weeks before Awareness Week, I count out pens, I print out colouring-in forms, I label little packets of pencils, I'm surrounded by little mounds of balloons, I unravel rolls of stickers and I stack up numbers of Red Cake Day branded serviettes.

As the orders come in, I take a bit of this and some of that and a bundle of those, package them up in a post bag and off the items go to our wonderful Red Cake Day and Awareness Stall organisers. Once the event is held, we receive the photos of their events and I see the bits and bobs I sent and know that my job is done!

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

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

Mr John Alexander OAM MP, Sharon Caris, HFA, and Joerg Hermans, Managing Director Biogen Idec, at Red Cake Day at Biogen Idec

The Red Cake Day team at Customs House

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

None of this type of work happens overnight, but it still seems a lot to have crammed into one year and I want to thank our staff and volunteers for this.

When I presented the President's report at the recent HFA Annual General Meeting, I commented that I thought 2014 had been one of our busiest years.

Our staff and volunteers work so hard every year that it is really hard to say that one has been busier than any other!

But we did have the launch of MyABDR and the 2014 World Congress at the start of the year and at this end of the year we have been considering some major changes to our Constitution. These are significant activities! Each of them could only occur with a lot of work in the background and very careful planning. None of this type of work happens overnight, but it still seems a lot to have crammed into one year and I want to thank our staff and volunteers for this.

HFA COUNCIL CHANGES

While the changes to our Constitution are yet to be ratified by the government regulatory authorities, they come from a resolution at the 2012 Council Meeting to replace the existing dual governance structure of our Council and Executive Board with a more efficient, agile and fully representative structure.

There will no longer be a separate Executive Board. All State/Territory Foundations will have one representative on Council and Council will meet at least three times each year. This is to enable quicker decision making and more timely responses on policy issues. We hope this will also improve formal communication opportunities between our member Foundations. There will be a process as before, to make sure communities without formal representation, such as South Australia and Northern Territory, can also have a say. We look forward to the time when we have the whole country fully and properly represented.

FOUNDATION WEBSITES PROJECT

Another major decision at Council was that HFA will work with its member Foundations redevelop the HFA and state/territory websites so they can sit together seamlessly to provide consistent, accurate and reliable education resources and information about our programs and activities. Each Foundation will have its own website and web address and retain control over updating its memberships, activities and other information, but this means the websites will be able to share some sections, such as educational information, or news items. There will be a new underlying web site structure which will also mean issues like web site accessibility – which are important for users, but complex for State and Territory Foundations - are taken care of nationally.

NEW CLOTTING FACTOR PRODUCTS

There is great interest in the longer acting clotting factor products that have been registered in Australia and for other products at the stage of human trials. We are at an interesting time and I look forward to hearing the views from our community members about the different types of products that could become available.

HEP C NEWS

Much is happening very quickly in new hepatitis C treatments.

A wave of new direct acting antiviral (DAA) hepatitis C drugs have been completing large-scale multi-centre clinical trials and are gradually coming before the Therapeutic Goods Administration (TGA) to be approved for use in Australia and before PBAC for government subsidy on the Pharmaceutical Benefits Scheme (PBS).

In clinical trials they have had very high success rates, few side-effects, and shorter treatment courses. Some need to be taken in combination with other medications (eg, interferon, ribavirin, ledipasvir) to be effective. Some will be available in interferon or ribavirin-free combinations. Some have had encouraging results even with people who previously had unsuccessful treatment or who have advanced liver disease[1].

So far:

- PBAC has approved adding simeprevir (Olysio™) to the PBS for the treatment of genotype 1 chronic hepatitis C
- 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. Sofosbuvir is likely to be resubmitted to PBAC in 2015
- Other new DAAs are likely to be submitted for TGA approval and PBS listing in 2015.

Professor Ed Gane from New Zealand explained more about these new DAAs at a 2014 conference in Brisbane – tinyurl.com/new-hep-c-treatments.

SO WHAT NEXT?

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

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

To clarify the current situation for affected people with bleeding disorders nationally – their need for treatment, potential benefits and issues relating to current and upcoming treatments - we have sought expert advice from the Australian Haemophilia Centre Directors' Organisation and from hepatitis specialists.

HFA will be following up with more representation to government on these new treatments.

AND FOR NOW?

Loud and clear the message is - if you have hepatitis C and a bleeding disorder:

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

REFERENCES

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

This article is the text of a presentation Neil Boal gave at the WFH World Congress in May 2014. It is reprinted with permission from *Missing Factor*, the magazine of Haemophilia Foundation Victoria (www.hfv.org.au), August 2014.

Neil Boal is an HFV member and former HFV President

DISCLOSURE - WHY AND HOW TO TELL ABOUT YOUR HAEMOPHILIA

Neil Boal

As dramatic as that sounds, preparing for possible outcomes can lessen any negative effects that may come your way.

There seems to be many reasons why not to disclose to people about your bleeding disorder. I say "reasons" and not "excuses" because whatever thoughts are concerning you about disclosure are usually very valid. I will focus on career and relationship disclosure as they seem to be the two main areas of concern.

AT SCHOOL

As a child and young adult the choice to disclose was not usually mine as my parents thought whoever or whatever I was involved in had to be informed in case of any accidents occurring. This of course was things like school and organised sporting activities.

Now, looking back, I can totally understand why, but at the time being "exposed" did have some negative impact. This started in secondary school in the form of verbal bullying mainly because I wasn't allowed to take part in many of the sporting activities.

My haemophilia was not obvious and most students and even some teachers thought I was faking. The irony there is that I went to that particular school because another boy with haemophilia was already there. However, he was much more severe and had braces on both of his legs, so that's what they thought I should have been like. However I didn't take too long to fit in by using my many charms and good looks to good effect. But there still remained a few who doubted me.

AT WORK

As I moved into adulthood the decisions around disclosure rested with me. My very first job interview loomed so I had to decide whether to disclose or not. I had both ankles and my right elbow as target joints and these were very unpredictable, so there was no doubt I would have a bleed at some point during my career.

My decision was to go in with an "honesty is best" policy. I explained to my boss the ins and outs of my haemophilia, along with the treatment, but also not forgetting to add in my good qualities as well. I did get the job and I was told my honesty had actually made the difference.

As I've changed jobs over the years being open about haemophilia has never been an issue. Having said that I went to work on many occasions with some very painful bleeds and that served the purpose of showing that if I did take a day off then it meant I was really sore and genuinely couldn't make it to work.

HIV AND HEP C

However I did change my honesty policy when I was diagnosed with HIV and hep C. Back then there was so much hysteria surrounding these viruses that there would be next to no hope of holding or even getting work at all.

This was about the time my wife and I moved interstate and we knew no one. We decided not to disclose anything about the haemophilia and I managed to get through five years without anyone being the wiser. I had an elbow frozen at about 90 degrees which was hard to disguise but I explained it off as an accident I had as a child and everyone was happy with that.

When my wife and I moved back to our home town then I was back to having to disclose my haemophilia. Though I was employed by people that didn't know me, the chances of them finding out from someone who did were quite high.

Again being honest about haemophilia wasn't a problem but now the concern was my health was deteriorating because of the blood-borne viruses. Over the course of a few years I had to negotiate reducing working hours, but I blamed my haemophilia (which was partly true).

Luckily I had good employers who valued me and were happy to keep me on. I think if anyone is good enough at what they do then I think a lot of employers would do the same. As I got older my joints began to decline rapidly and it was a combination of health problems that forced me into retirement in my mid-forties.

RELATIONSHIPS

Moving onto relationship disclosure; now, I can't spend too much time on this as my girlfriends at school all knew about my haemophilia and my wife knew through our common circle of friends, and we were already a

couple when we found out about the HIV and hep C.

However, I have seen the effects of people in relationships that have hidden things and this can be disastrous when the relationship gets serious. Nobody like secrets and the fact is the longer you hide a secret, the more difficult it is to talk about and the harder it is to hide. Similarly if you spin a web of lies, you have to remember them and often create more and you can end up in a hell of a deep hole that you may never get out of. It also creates a level of distrust that may be hard to dispel.

So what advice can I offer on disclosing your haemophilia or blood borne virus?

First you must identify the situation and how important it is to you.

Is it for career or personal reasons?

Either way it's a personal decision that, once out there, can potentially, have a significant impact on your life.

As dramatic as that sounds, preparing for possible outcomes can lessen any negative effects that may come your way.

So let's explore the scenarios mentioned above.

Career: Firstly you have to identify if you legally have to disclose your disorder. If you've chosen to pursue a career with a health element to it like the Armed Forces or Police Force then you should arm yourself with all the available up-to-date information on haemophilia plus a personalised letter from your specialist supporting your argument that you believe you can do that profession. You may even need to get some legal advice.

In other normal low risk careers then it's up to you if you wish to disclose. You know your body and whether you could competently carry out your duties. If you do choose to disclose then give your potential employer some confidence in how well your condition is managed and it should rarely, if ever, inhibit your duties but you just wanted to inform them to be honest with them.

If you decide not to disclose then that's ok too, but you really need to be super diligent with your care to minimise time off. Often these days businesses have team building exercises that may prove a problem for you if it's really physical, so be aware, you may need to treat beforehand.

Relationships are a different ball game. I believe you have to be honest. That doesn't mean to go and blurt out everything on the first date, but if you think things could get serious then fess up sooner rather than later. Reassure your partner that haemophilia is just a small part of you and then give them as much information as they ask for, but don't overload them.

At some stage you may want to take them along to see your specialist or social worker.

Your partner may even want to have a private meeting too so they can ask questions they might not want to ask you. I think you should support this as this shows you have nothing to hide. You would have to give your doctor or social worker permission though as they have your confidentiality to uphold.

Your Haemophilia Centre or Foundation can be a great help too by providing information booklets on many different topics and are terrific at offering avenues for peer support which can be the most useful of all tools.

To finish, I have found being open and honest about haemophilia and my BBVs has been very positive for me. It's actually opened doors for me and created some opportunities I would never have got otherwise. I've met some great people along the way all the while creating awareness, often inadvertently.

If you view your disorder with a positive attitude then people tend to be positive towards you.

For more information on disclosing hepatitis C if you have a bleeding disorder, see the My choice to tell fact sheets on the HFA web site www.haemophilia.org.au.

Photo: International AIDS Society/Steve Forrest

WORLD AIDS DAY 2014

GETTING TO ZERO

World AIDS Day is marked globally on 1 December.

This is a time to raise awareness in the wider community about the issues surrounding HIV and AIDS. It is a day to demonstrate support for people living with HIV and to commemorate those who have died. Wearing a red ribbon is an internationally recognised way of showing solidarity and raising awareness of HIV.

This is also a time when we remember the members of the bleeding disorder community who were affected by HIV when in the mid-1980s HIV was transmitted through some batches of clotting factor treatment product. As a result of this tragic episode, some people lost partners, family members, children, patients, colleagues and friends.

Some people with bleeding disorders continue to live with the challenges of HIV; and we acknowledge the individuals who inspire us by their positive attitude, resilience and determination to build a better future.

In 2014 the World AIDS Day global campaign continues the theme of:

Getting to zero

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

In Australia, the aim is to encourage all Australians to:

- Be aware that HIV still exists in the community
- Take action to prevent transmission of HIV by promoting safe sex practices
- Support and understand people living with or affected by HIV
- And uphold the right of people living with HIV to participate in the community free from stigma and discrimination.

AIDS 2014

In July 2014 the International AIDS Conference brought 13,600 delegates from over 200 countries to Melbourne with a theme of ***Stepping up the Pace.*** It was an exciting and inspiring event. Conference sessions reflected on the impact of HIV on the local community, including among people with bleeding disorders, and the strength of the response in Australia. The Conference also looked to the future, with the promise of a "cure" for HIV, new, safe and effective hepatitis C treatments for those co-infected with HIV/HCV, overcoming discrimination, and programs and strategies for people living with HIV who are now moving into their senior years.

In this issue of *National Haemophilia* we celebrate ***Stepping up the Pace*** with articles on:

- HIV remission as a potential cure for HIV
- An update on new hepatitis C treatments
- Disclosing your bleeding disorder and BBVs.

For more information about World AIDS Day, contact your local HIV organisation or visit www.worldaidsday.org.au.

This article is reprinted with permission from *Positive Living*, the magazine of the National Association of People With HIV Australia (www.napwha.org.au), September 2014

Neil McKellar-Stewart is the HIV Health Maintenance Officer at ACON's Northern Rivers Office

REMISSION POSSIBLE

Neil McKellar-Stewart

While a cure for HIV remains elusive, sustained remission maybe the next best thing.

To date, there have been several instances of HIV remission (remission being when the virus is not active enough to require treatment).

Arguably the most famous case is the 'Berlin patient' - Timothy Brown - who, after a bone marrow transplant, remains off treatment and virus-free six years on. And, as revealed at AIDS 2014, two Australian HIV patients have also been discovered to be virus-free.

The latest science on remission strategies was very much the focus of a two-day, pre-conference satellite symposium, ***Towards an HIV Cure***, attended by around 300 researchers and community representatives from around the world.

Whilst antiretroviral treatment (ART) drives HIV viral load to undetectable levels, some HIV remains circulating in the blood. Additionally, a 'reservoir' of long-lived immune system cells containing HIV persists indefinitely. HIV can awaken from this reservoir and enter the circulation system. That's why - as recently evidenced by the 'Mississippi baby' and the 'Boston patients' - viral load rapidly returns to pre-treatment levels once ART is discontinued.

But what if this latent reservoir of HIV could be awakened, attacked and killed? A Danish trial - headed by Ole Søgaard of Aarhus University Hospital, Denmark - assessed the safety of a cancer drug called romidepsin and to what extent it can reactivate HIV from latency. This was a small non-randomised interventional trial involving six patients with HIV who were given romidepsin three times a day for 14 days.

The results were mixed: promising as far as safety and the effect on inducing reactivation from latency; and perhaps disappointing as far as revealing any significant change in reservoir size. Still, the Danish study is regarded as a big step forward to finding a vaccine for HIV. A clinical trial combining a therapeutic vaccine (Vacc-4x) and romidepsin is ongoing.

Meanwhile, Dr Vicente Planelles of the University of Utah, USA, reported on a new family of heterocyclic compounds (benzotriazole analogues), which in laboratory studies very effectively reactivated latent cells containing HIV. One of the appealing features of these compounds is that they don't increase some of the chemical messengers that cause inflammation and other cell damage.

When tested with T cells from HIV-positive people, one of these compounds was able to reactivate virus from people with undetectable viral loads. The symposium heard of other compounds under lab investigation which stimulate HIV replication through different mechanisms. Together, these new compounds add a whole new range of possibilities in shocking HIV out of latency.

Other research presented at the symposium related to work being done on targeting and killing HIV sanctuaries in tissues.

It has been known for almost a decade that lymph-node follicles produce a range of immune cells and are sites where HIV replication is active and where substantial reservoirs of HIV are located.

Dr Rama Amara (Yerkes National Primate Research Centre, Emory University, US) reported research in rhesus macaque monkeys which were vaccinated against, and then challenged by, infection with SIV (the monkey form of HIV). Compared to the unvaccinated monkeys, the vaccinated macaques had much lower proportions of HIV-infected cells (in blood, lymph nodes and rectal tissues). They were also found to have higher proportions of CD8 cells able to kill HIV-infected CD4 cells.

This data suggests it may be possible to develop vaccine-based therapies to reduce or eliminate virus-infected cells. Exciting news indeed, indicating that much more is being discovered about, not only where HIV hides but, more crucially, how to eradicate it. Conference chair Françoise Barré-Sinoussi - who discovered the HIV virus - believes remission is more achievable than cure. And while acknowledging there will be rebounds along the way, she remains optimistic that sustained remission strategies will be found.

"To achieve long-term HIV remission we will likely need to tackle the problem on multiple fronts," said Barré-Sinoussi. "Lowering as much as possible the number of long-lived, latently infected cells present in the body, as well as bolstering the host defence. One cannot be done without the other."

Expect to hear a lot more about interventions that might lead to sustained HIV remission. Australia is more than lifting its weight in this regard, continuing to contribute funding and expertise to remission research. As the cure symposium showed, progress towards remission is accelerating and the latest research suggests that the prospect of an AIDS-free generation is indeed within reach.

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

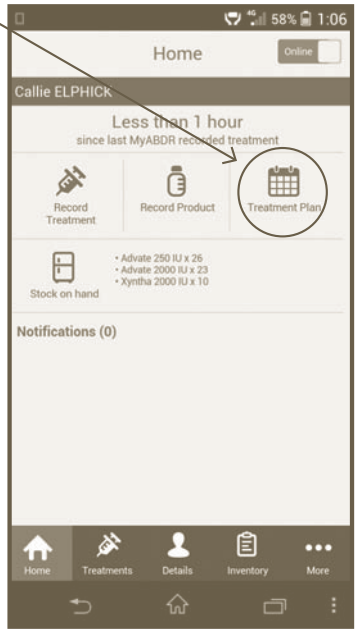
MYABDR UPDATE

Suzanne O'Callaghan and Peter O'Halloran

WHAT'S NEW?

The latest release of MyABDR in November 2014 brought you further improvements and features:

- **Faster synchronisation,** more than halving the amount of time synchronisation takes - and data will always be captured in the central database, even if an error occurs on your smartphone
- **A short-cut to your treatment plan** from the home page or screen – making it quicker and easier than ever before to get to this key information
- **Bug fixes to address negative stock levels** some users have reported
- **An improved function to copy previous entries** for "ADD NEW TREATMENT" and "RECEIVED PRODUCT" to prevent the unintentional double-entries experienced by some users



- **Easier treatment product entry** – you will now only have the products in your treatment plan to choose from when adding products to your inventory.

UPDATING WITH THE NEW RELEASE

Why **update your smartphone** with the latest release?

It only takes a couple of minutes - and will mean your app will include all the new fixes and features, making your life easier!

Finding out about new releases:

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

Then either

- Tap on the UPDATE notification on your phone screen
- Follow the steps to install the new release.

OR

- 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 and sync your data at the home page before you uninstall the app!

What 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?

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

FEEDBACK

Your feedback is always welcome and your comments will be used to improve MyABDR.

Ways to give feedback:

- Talk to the MyABDR Support Team
  T: 13 000 BLOOD (13 000 25663)
  E: myabdr@blood.gov.au
- Via the HFA MyABDR Have Your Say Feedback form – www.haemophilia.org.au/myabdr
- Contact Suzanne O'Callaghan at HFA
  T: 1800 807 173
  E: socallaghan@haemophilia.org.au

The brothers and their cousin with haemophilia

Julia and Rebecca and their families are members of the Australian bleeding disorders community.

HAEMOPHILIA
ALL IN THE FAMILY

Two sisters, Julia and Rebecca, who both carry the genetic alteration causing haemophilia, tell their story of growing up and having families. Between them they have four sons, all toddlers - and three have haemophilia.

"Haemophilia has always been a part of my life, and my family's life – my dad has haemophilia and we grew up in an environment in which he chose not to let it dominate. Most of the time it didn't alter his or our lifestyle choices, but the times he had a bad bleed it involved some real challenges for him and the rest of the family in managing the bleed and the subsequent recovery," said Julia.

Julia's boys are 4 and 2 years old, both with moderately severe haemophilia. Rebecca has one son who is 3 years with severe haemophilia – but her youngest, who is not yet a year old, does not have haemophilia.

CARRYING THE GENE

Although both sisters carry the genetic alteration that causes haemophilia, they have each experienced this differently. Julia has never had any bleeding symptoms, while Rebecca has always bruised easily. She commented that generally this was never a great problem for her. The only time she ever had treatment product was when she was given some recombinant factor VIII (8) coverage for a knee reconstruction as a precaution. Bruising too was not usually an issue - except when she was about to start at a new school and didn't know anyone else there. "A few days before my first day of Year 7, I had been jumping on my sister's bed and banged my eyebrow really hard and got a bad black eye," recalled Rebecca. "By the time my first day of school came around the bruising had spread to the other eye, so I had two eyes in various shades of purple, black, brown, blue and green. That was quite a challenge when I just wanted to blend in with the other kids!"

FAMILY PLANNING

Both girls were very open with their partners about haemophilia and their carrier status. And both partners responded in a very positive way. "For us my carrier status was not really an issue," said Julia.

Julia and Rebecca had genetic counselling before starting a family. Julia also had genetic counselling during pregnancy, "though we chose not to test our babies for haemophilia in utero – instead going into my labour prepared for the eventuality that our baby did have haemophilia, in case of birth complications."

Rebecca commented that family planning issues were perhaps less complicated for them than the situation other parents might face. One reason related to their family experience of haemophilia. Their father has moderate rather than severe haemophilia and, while the home infusions, the trips to and extended stays in hospital have been a regular part of his life, he has also been very involved in sport since he was young. "My Dad has always tried hard not to let haemophilia change his lifestyle and he has remained physically active. This was a great role model – particularly for my husband who had no prior exposure to the condition. So my husband and I were of the view that we'd deal with whatever came," explained Rebecca.

Understanding the advances in treatment in recent years has also made a difference. Their father is now dealing with the long term health impact of having haemophilia – "years of joint bleeds have left him with some bad arthritis which affects mobility," noted Rebecca. He also has liver disease from hepatitis C acquired from his treatment before screening and viral inactivation was introduced in 1990. In contrast, their sons will have the advantage of prophylaxis treatment to prevent and manage bleeds and recombinant clotting factor product, which is genetically engineered, contains little or no human or animal material, and has not been known to transmit viruses.

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"I think there's a lot to be said for finding out as much as you can," remarked Julia. "Without an understanding of haemophilia, the treatment options and what that means for the chance of living an 'almost normal' life, haemophilia can be quite daunting. But these days the prospects of a fulfilling and relatively pain-free life are really good and once you realise this, it's easier to accept. A lot of people talk about the 'guilt' of passing haemophilia on in a family but I don't view it like that. I (and I think my family too) have been accepting of haemophilia and remain hopeful that the recent advances in treatment will continue."

For the sisters, the process of family planning and genetic testing was a very personal decision and one which they thought would be different for each woman or couple. "It's your decision, take your time, do what you need to do, talk to whoever you need to talk to," said Rebecca.

DEALING WITH DIAGNOSIS

Even after careful planning, diagnosis was challenging.

"I do recall a sense of shock when we found out our first baby had haemophilia," commented Julia. "Perhaps it was simply that we always quietly hoped that the answer would be 'no' and the 'yes' immediately signalled a whole new reality for us (even if it was one that we had thought through in advance).

"But I think the real sense of shock came from finding out our baby's factor levels: less than 1%. We'd been told factor levels generally 'run true' in a family, and my dad's levels were 4-6%, but I knew that less than 1% was classified as 'severe' and was something altogether different to 'moderate' haemophilia. We were immediately put in touch with a paediatric haematologist and I remember the first few months in particular being quite scary as we tried to get a feel for the degree of our boy's haemophilia. However, since birth their levels have varied and In fact, we've been very pleasantly surprised – both by our first boy and our second, who was also diagnosed as moderately severe – at the relative infrequency of their bleeds and their ability so far to live like normal toddlers."

Rebecca had a similar experience of shock when finding out her son's initial factor levels, which were less than 1%. "Having our first newborn was such a new experience, that this was just another thing in the mix to work out how to deal with (along with nappy changes, feeding etc etc!). Our short time living in the US with a child with haemophilia gave us a small insight into some of the challenges associated with health insurance coverage and the high cost of product."

Ironically, having a child that doesn't have haemophilia has added a little more complexity to Rebecca's family.

"When our second son came back negative to haemophilia, it was a strange feeling. Of course we felt the relief that he wouldn't have to deal with hospitals and needles and all the challenges along the way. However, it also felt a bit strange, as his big brother, two cousins and grandfather all have haemophilia, so in a way he'll be the 'odd one out'," said Rebecca.

The recent World Congress in Melbourne proved to be a great environment for Rebecca to learn about the experiences of siblings who don't have haemophilia and strategies for parents such as involving the siblings in treatment and care, helping to prepare infusions, and other ideas.

"Our little one is only 11 months now, so we'll deal with this further down the track. In the meantime though, we're all off to our first family camp later in the year so this will be a whole-of-family experience!"

HAEMOPHILIA IN FAMILIES

- Haemophilia is caused by an alteration in the gene making factor VIII (8) or IX (9)
- Women and men can carry the genetic alteration causing haemophilia and pass it on to their children
- Many women who carry the gene do not have bleeding symptoms.
- Some women who carry the gene can have a bleeding tendency
- Symptoms in women include bruising easily, heavy or long menstrual periods, bleeding for a long time after childbirth, surgery, medical procedures, dental extractions, injuries or accidents
- Females with very low clotting factor levels may also have joint or muscle bleeds
- In the vast majority of cases the males with haemophilia in a family will have the same level of severity, but this is not always the case.

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

Rebecca, Julia and their father

HFA WOMEN *AND* GIRLS'
PROJECT UPDATE

WOMEN'S PROJECT
You may have noticed some personal stories from women with bleeding disorders or who carry the gene in recent issues of *National Haemophilia*.

This is part of the work of the HFA Women's Project. Thanks to the women who have agreed to be part of the project and share their experiences or contribute to the new HFA education resources!

The education resources include two booklets for women, one on carrying the gene for haemophilia and the other on living with a bleeding disorder. They are underway and being drafted as we speak. They will be available in print and online.

HOW TO BE INVOLVED?
If you are a woman who carries the gene or have bleeding symptoms, and would like to be involved in the project, it's not too late - contact Suzanne O'Callaghan at HFA:

E: socallaghan@haemophilia.org.auT: 1800 807 173 (Mon-Fri)

You can:
- Tell your story for *National Haemophilia* and/or the new resources

And/or
- Contribute by giving your comments on the draft resources.

INFORMATION FOR YOUNG WOMEN AND TEENAGE GIRLS
We have had a great response from young women and teenage girls with bleeding disorders and parents – thanks to all who have completed the online survey!

Your answers and ideas will be used to develop information resources specifically targeted at young women and teenage girls in the 13-25 age group. These are being developed in addition to the two new booklets for women.

For more information about the project for young women and girls, contact Hannah Opeskin at HFA:
E: hopeskin@haemophilia.org.au
T: 1800 807 173 (Mon, Tue, Fri).

This article is reprinted with permission from *Bloodline*, the magazine of Haemophilia Foundation New Zealand (www.hfnz.org.nz), September 2014.

Sarah Elliott is Haemophilia Outreach Worker – Northern, Haemophilia Foundation of New Zealand

DEALING WITH BULLYING

Sarah Elliott

Both children with and without haemophilia get bullied. Although children with special health needs such as a bleeding disorder can be at an increased risk of being bullied, haemophilia may not be the cause of bullying (in most instances it is NOT about haemophilia). Why a person is being bullied is hard to determine or change, but there are many things we can do to try to deal appropriately with the bullying.

Bullying is unacceptable and can really hurt people and have lasting effects. Violent behaviour by a bully can result in bleeds for children with bleeding disorders like haemophilia, so it can be more dangerous than for most kids.

Parents and other adults in a child's life should take bullying seriously. This means knowing and understanding what bullying is and applying strategies to help your child deal with bullies.

WHAT IS BULLYING?

Bullying behaviour is when someone, or a group of people, says or does something that hurts, embarrasses, frightens or upsets somebody else on purpose. It is aggressive and intentional behaviour that involves an imbalance of power. Being bullied can leave someone feeling sad, lonely, scared, and worried. Most often, bullying is repeated over time and sometimes has been around for many years.

In contrast, some behaviour such as light teasing or saying something mean in the heat of the moment is not bullying as it is not done over time or intentionally causing harm.

Although they can still be hurtful, these types of behaviours take place for all children in testing friendship and social boundaries.

Many people do not realise that bullying comes in different forms that include:

- Physical - hurting a person's body or possessions
- Verbal - saying or writing mean things; threatening
- Social - hurting someone's reputation, embarrassing someone, not talking to them, leaving them out of joint activities or spreading rumours
- Cyber - using social media or texts to target and cause harm to others.

With teens, bullying can also have a sexual content to it and may involve sexual harassment.

SIGNS A CHILD IS BEING BULLIED

Bullying can make children and young people feel lonely, unhappy and frightened. It can make them feel unsafe and think that something must be wrong with them. They can lose confidence and may not want to go to school or other social activities.

It is hard to know if a child is being bullied, but there are some signs to look out for.

Has your child been:

- Coming home with cuts and bruises or torn clothes?
- Taking a different way to school or home?
- 'Losing' possessions, money or food?
- Moody and easily upset, quiet and withdrawn?
- Aggressive with brothers and sisters?
- Having trouble with school work?

STRATEGIES TO DEAL WITH BULLYING OR BULLIES

A workshop on bullying was held at a recent HFNZ regional camp. Together members of HFNZ's Northern branch discussed strategies to deal with bullying or bullies, both as recommended by professionals and from their own experience. The following is their list of approaches and strategies. Please note: not all of the listed strategies will work for your child. All children are different so something might work for one and not another – it is about seeing what is the best fit for you and your family.

- **Keep communication open** – allow your child to express their feelings and emotions. They may like to write in a journal or express their feelings in other ways. As a parent just listening and understanding can help. If your child is telling you about their feelings it is a BIG first step.
- If you think your child is dealing with bullying but they do not talk about it then **try to engage them gently –** let them know that you see something is upsetting them and that when they are ready to talk about it you are ready to listen, you are there for them. Or let them know if they want to talk to someone else they could

talk to another relative, teacher, and mentor or call a helpline (details below).

- If your child doesn't engage easily with you **try having a chat at meal times** or before bed and ask about specific things at school and in the class (not just 'how was your day') or just sit with your child and don't say anything and they may open up.
- **A safety plan** is great – 'who to tell if…', 'what to do if…'. Go over this plan many times with your child so they feel confident of how to interact with a bully, or what to do when bullying arises.
- **Encourage them to say 'stop it'** or 'leave me alone'. Encourage them to call out the behaviour 'don't hit me' or 'stop throwing things at me' – get them to practise what they might say to the bully.
- **Encourage them to act tall and strong:** hold their head up, make eye contact, use a calm and firm voice, and give a poker face to show confidence.
- **Teach your child what to react/respond to and what to ignore.** There are times when walking away or acting unimpressed are better than confronting the bully.
- **As a parent learn to control your own emotions** about the situation and try to look at it logically.
- **Keep a bullying record** – who did what and when to your child. This can be helpful to keep perspective on the situation and to show teachers.
- **Get to know your community and other parents** at your school or in your child's class. By being connected or friends with other parents you could prevent bullying happening or quickly respond to it.
- It is hard for kids to know how to respond to bullies/bullying so **do not make them feel bad about their initial response,** even if you do not think it is the right course of action. Gently give them some other little ideas/tips for them to try next time
- **Let your child know you are on their side** and that you believe them.
- **Validate and congratulate your child when they have dealt with the situation well,** i.e., told you or a teacher.
- **Do not encourage name calling or violence** as a form of retaliation as it will just escalate the situation.
- Help **nurture friendships with a non-bully,** as having buddies can make dealing with bullying easier.
- Focus on building their resilience and self-esteem generally through **supporting their interests and talents.**
- **Find places/hobbies that are away from the bully** and in places where they will feel accepted.
- **Encourage them to do things they enjoy like** playing games, listening to music, reading books, playing sports, and hanging out with caring people. This might not stop the bullying, but it will help them manage their feelings, and help them to get through the tough times.
- **Let them know bullying is never OK;** it's not cool and that it is not their fault or something they 'deserve'. Let them know everyone has the right to feel safe and be treated with respect.
- **Identify behaviour or actions which might aggravate the bully** and try to curb them if appropriate and if there is a trigger.
- **Educate your child generally about bullying and bullies.**
- **Encourage your child to come up with the solutions** – What do they think might work? What do they think might make them feel better? Who would they like to talk to at school if it happens?
- **As a parent talking to the school teacher or school counsellor** about bullying is a good idea – so they can keep an eye out for your child or address it with the bullies in an appropriate way.
- **Ask the school for its policy on bullying** so you know what action they take.

Even after the bullying has stopped the child might need to deal with the effects.

Violence is not a way to deal with bullying or any of life's problems. If we encourage a child to use violence whilst young, then they will often use it as a way to continue to deal with what life throws at them or as a coping mechanism and this is not good for anyone – especially someone with a bleeding disorder.

FOCUS ON CYBERBULLYING

These days, kids not only socialise in the physical world, but also in the virtual world. This has created what is now known as cyber-bullying. Cyberbullying is bullying that happens online. It can happen in an email, a text message, an online game or on a social networking site. It might involve rumours or images posted on someone's profile or passed around for other people to see.

Cyberbullying takes many forms and some of these may be harder to deal with than others. Depending on the situation, some young people are able to sort it out quickly, or simply shrug it off. Other situations may be more serious. About 1 in 5 New Zealand high school students say they have been cyberbullied and many say it makes them feel scared, depressed, angry or ashamed.

Receiving nasty messages outside of school can make it feel hard to escape the bullying. Some people say it's worse if you can't tell who the bullying messages are coming from.

Posting mean or nasty pictures or videos of people online can embarrass them in front of their school and spread quickly out of control. If you or your teen posts altered pictures of people online these can exist long after you delete them and can also be used as evidence by teachers and police.

What can you do to prevent cyberbullying?

- Be careful who you give your mobile number to and don't pass on friends' numbers without asking them first.
- Don't respond to texts from people you don't know. These can often be sent randomly to find people to bully.
- Don't post revealing pictures of yourself or others online - they may get sent on and used to bully you or other people.
- Keep your online identity safe - create strong passwords with a mix of lower and upper case letters and numbers. Pick difficult answers for your "secret question" on your accounts that people who know you wouldn't easily guess and don't share your password with anyone - even your friends.

What if you or your child is being cyberbullied?

- Tell people you trust - a good friend, a parent, or a teacher. They will want to help you stop the bullying quickly and safely. You can also report bullying to the police, even anonymously if this feels safer.
- Do not reply to the people bullying you, especially to text messages from numbers you don't know.
- Save evidence of all bullying messages and images. You can save messages on your phone and take screen shots of bullying on websites or IM chats. This may be used later if you report the bullying.

As a parent, educating your kids about cyberbullying is the first step to creating awareness around this important issue. Talk to your kids about the risk when being online. Start early and create an honest, open environment. Ask them to tell you if an online message makes them feel threatened or hurt. Keep an open channel of communication with your child, and hopefully he or she will come to you.

FURTHER RESOURCES:

Kids Helpline – is Australia's only free, private and confidential, telephone and online counselling service specifically for young people aged between 5 and 25.

Call 1800 55 1800 or visit www.kidshelp.com.au

Bullying Blocking – A social survival model to enable to cope with bullying.

Visit www.bullying.com.au

Bullying. No Way! – managed by the Safe and Supportive School Communities (SSSC) Working Group

Visit www.bullyingnoway.gov.au

National Centre Against Bullying - a peak body working to advise and inform the Australian community on the issue of childhood bullying and the creation of safe schools and communities, including the issue of cybersafety.

Visit: www.ncab.org.au

‘CHANGING POSSIBILITIES IN HAEMOPHILIA®’ *GRANT*

Desdemona Chong

The Changing Possibilities in Haemophilia® grant program is set to provide funding for an innovative new project to advance haemophilia care in Australia through a series of psychosocial skill patient workshops in 2015.

The independently adjudicated grant program, now in its third year, was established by Novo Nordisk to support new projects and initiatives to be implemented by nurses, physiotherapists, psychologists and other professionals working in haemophilia care.

GRANT AWARD

The recipient of the 2014 Changing Possibilities in Haemophilia® grant is Dr Desdemona Chong, Clinical Psychologist from the Queensland Haemophilia Centre for the **‘Enhancing life-skills, empowering life changes – Another step towards comprehensive care’** project.

The lead investigator Clinical Psychologist Dr Desdemona Chong has been involved in a broad range of activities to support haemophilia care including the development of haemophilia patient educational resources, has contributed to various advocacy initiatives as well as research projects that aim to enhance psychosocial outcomes, and she has been providing psychotherapy and counselling to people living with haemophilia for a number of years.

“The impact of having a chronic health condition, such as an inherited bleeding disorder, goes beyond medicine,” said Dr Chong. “Specific to persons with haemophilia, research suggests that psychosocial factors better predict variation in quality of life than clinical factors. One of the ways to enhance coping is to empower individuals with life-skills to manage the psychosocial challenges.”

The aim of the project is to enhance the coping skills of patients under the care of the Queensland Haemophilia Centre (from both metropolitan and regional areas) through a series of workshops that focus on enhancing the psychosocial skills of individuals, as well as post-workshop follow-up support. Four full-day workshops will be held throughout 2015 and will cover topics such as pain management, communication, relationships, relaxation and issues related to carrying the haemophilia gene using a multi-disciplinary approach.

The judges felt Dr Chong’s project will provide workshop participants with useful strategies to help them deal with the ongoing health issues related to haemophilia.

MORE INFORMATION

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

If you would like further information about the Changing Possibilities in Haemophilia® grants program, please email your details to the secretariat at info@cube.com.au

‘Enhancing life-skills, empowering life changes – Another step towards comprehensive care’

Sulochana B is Associate Professor at Manipal College of Nursing, India

HAEMOPHILIA NURSING CARE – A CHANGED OUTLOOK

Sulochana B.

The International Hemophilia Treatment Centre (IHTC) Program offers fellows a unique opportunity to learn about haemophilia diagnosis and management from designated bleeding disorders specialists. Fellows are assigned to one of the designated IHTCs of the World Federation of Hemophilia (WFH) where they undergo four to six-week training.

The Alfred HTC has trained five nurses: two from China, two from Malaysia and Subbi (Sulochana B.) from India. The program is organised around the professional interests and needs of the IHTC fellow. Subbi wanted to learn about paediatric haemophilia care so we were able to schedule some time at the Royal Children's Hospital, Melbourne and The Children's Hospital, Westmead in Sydney.

It's a great experience for the Australian nurses to work with nurses from developing countries - it keeps us grounded and also reminds us how much can be done with so little!

Penny McCarthy and Megan Walsh

Clinical Nurse Consultants
Ronald Sawers Haemophilia Centre, The Alfred, Melbourne

To start with I quote John Stuart Mill, who says, "there are many truths of which the true meaning cannot be revealed until personal experience has brought it home". This truly is how I look at my experience in Australia.

It was a wonderful opportunity for me to take up the recent International Hemophilia Training Fellowship during August and September 2013 at Ronald Sawers Haemophilia Centre at The Alfred hospital, Australia.

I am grateful to the World Federation of Hemophilia (WFH) for awarding the International Hemophilia Training Centre (IHTC) Fellowship to me in 2012. And I am thankful to the Hemophilia Foundation India for nominating me for the IHTC Fellowship.

This visit covered nursing observation in three large haemophilia treatment centres in Australia: The Alfred hospital, and the Royal Children's Hospital in Melbourne and The Children's Hospital at Westmead in Sydney.

It was a great opportunity for me to be exposed to the treatment modalities and management aspects of haemophilia care that relate to Indian nursing care of patients with haemophilia, bleeding disorders and other general patient care. I saw it as a stepping stone for improvement in care and clinical management decisions in our setting in the future. I personally acquired a large amount of professional knowledge on haemophilia patient care from interacting with doctors, nurses and other members of the healthcare team, and feel confident I will be able to pass this information on.

HAEMOPHILIA IN MANIPAL, INDIA

My association with haemophilia care began at the Hemophilia Society, Manipal (MHS), which is a registered chapter of the Hemophilia Foundation India, New Delhi and affiliated to the WFH. The MHS functions from Kasturba Hospital, Manipal, Manipal University (www.manipal.edu), Karnataka, India. The Manipal University supports the MHS in its various activities for the care of patients with haemophilia and other bleeding disorders. The MHS has 295 patient members with 205 patients with haemophilia A, 39 with haemophilia B, 41 with von Willebrand disease, and 10 with other bleeding disorders. The patients are from the nearby districts of Karnataka and northern Kerala. My role as the haemophilia nurse co-ordinator at our Society involves identification of new cases, and training local healthcare workers in caring for persons with haemophilia and other bleeding disorders, along with patient education and counselling.

Assoc Prof Huyen Tran, Sulochana B and Penny McCarthy at the Ronald Sawers Haemophilia Centre in Melbourne

HAEMOPHILIA IN AUSTRALIA

State-of-the-art-facilities: The haemophilia treatment centre provides comprehensive care which consists of diagnosis, treatment, and management of haemophilia and other inherited bleeding disorders. An accurate diagnosis is quickly established, the family is educated on management, and the child is put either on prophylactic factor replacement or on-demand replacement given at home. With this type of treatment most children with haemophilia can go to school, enjoy sports, and expect to have minimal or no joint bleeding.

Comprehensive care by the Haemophilia team: responsibility is shared across the team. Patients are seen by physicians, nursing staff, physiotherapists, and social workers to provide care that covers all aspects of the disease to promote better living. They also work closely with specialists from dental orthopaedics, infectious diseases, gastroenterology, and obstetrics/gynaecology.

Treatment modalities: Replacement of the deficient factor VIII or IX through recombinant or plasma-derived concentrates is the mainstay of treatment for haemophilia. In case of inhibitors, bypassing agents (Feiba, recombinant factor VIIa) are provided to the patients.

The nurses at the centre have an important role. They:

- Help families deal with the day-to-day problems related to haemophilia
- Answer families' questions over the phone or at the clinic
- Provide out-patient care at the clinic
- Teach families how to do home therapy.
- Organise the delivery of factor concentrate for home use
- Co-ordinate appointments with other members of the comprehensive care team
- Are actively involved in research activities related to haemophilia and other bleeding disorders.

During the training I was able to learn a great deal through the resources and opportunities for observation provided to me. It helped me to update my clinical skills in caring for people with haemophilia and other bleeding disorders and to understand the scope of education and research in the areas of bleeding disorders. I was able to build skills in counselling patients, parents and carriers affected with haemophilia and other bleeding disorders. I also learned about database management of people with haemophilia and record keeping for effective analysis. Witnessing self-infusion of clotting factor concentrates by the haemophilia patients was a very new experience to me, and quite an eye opener.

I acquired very good resources on patient teachings like port care in person with haemophilia, home therapy, protocols, guidelines; CDs on joint health, home care and best practices etc.

HAEMOPHILIA IN DEVELOPING COUNTRIES

Unfortunately, the situation is very different for more than two-thirds of persons with haemophilia, who live in developing countries. In most of these countries the government does not have the resources to buy the necessary quantities of coagulation factors in the face of more urgent health priorities and hardly any patients can afford to pay for their own treatment, even for on-demand home therapy.

When resources are scarce, education is the cornerstone of haemophilia care. This should be the first major emphasis when organising haemophilia services in developing countries.

The Nurse Co-ordinator role within the comprehensive haemophilia team is still evolving in India. Against this backdrop I would say there is a need for a nurse's forum in India in collaboration with Hemophilia Federation of India, which will support quality care for people with haemophilia and other bleeding disorders.

The comprehensive haemophilia care teams, where nursing had a distinct role and voice, have provided me with inspiration for developing the same role for Indian nursing staff who care for children with haemophilia, both at the bedside and in a specialty role.

Finally I would like to conclude by saying that it was a real life altering experience. And I am extremely thankful to all who made my stay so meaningful. Thank you one and all.

FURTHER READING

Chandy, M. Treatment options in the management of hemophilia in developing countries. Treatment of hemophilia, no 37. Montreal: World Federation of Hemophilia, 2005. (available online at www.wfh.org).

Michael Hockey is Advanced Physiotherapist, Haemophilia,
Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital

HAEMOPHILIC ARTHROPATHY ASSESSMENT WITH THE USE OF ULTRASOUND

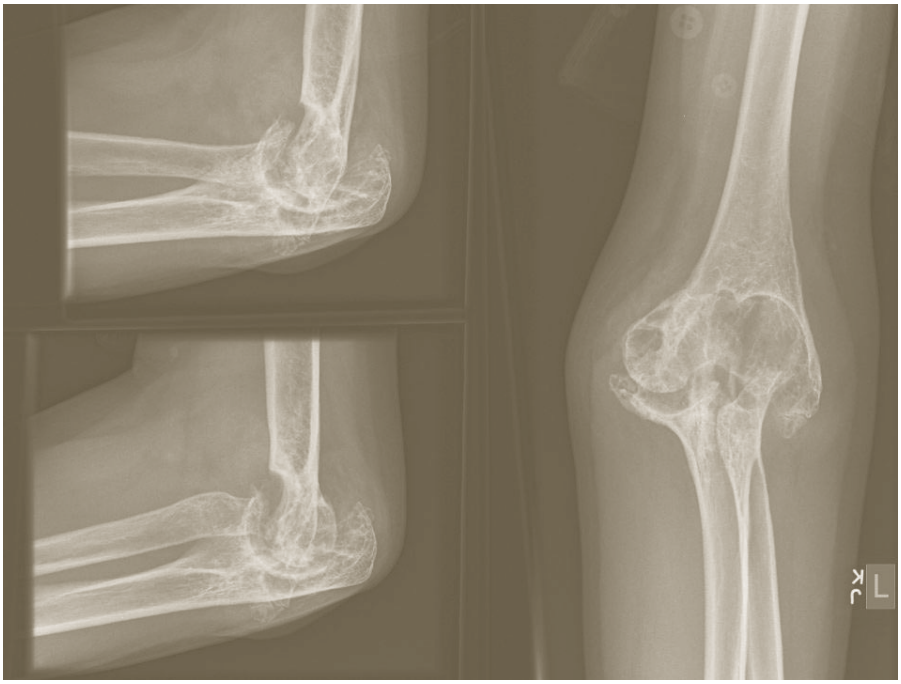
Michael Hockey

Haemophilic arthropathy refers to permanent joint disease occurring in people with haemophilia as a result of repeated bleeding into the joint. Medical Imaging (eg. X-ray) of affected joints has long been recommended as playing an important role in assessment. Ultrasound scanning is one type of imaging that has been proposed as a useful diagnostic tool in the assessment of haemophilic arthropathy.

Repeated joint bleeds causes damage to the joint surface. Healthy synovial tissue, the membrane lubricated by synovial fluid in freely moving joints, is very effective at clearing blood from the joint after an initial bleed. However, after the insult of multiple bleeds the synovium becomes chronically inflamed. It also becomes less able to clear blood and its waste products from the joint. Iron, which is a component of blood, builds up in the joint leading to the death and disruption of cartilage cells. This leads to a progressive destruction of the joint surface. Secondary changes include the formation of cysts and osteoporosis.

Often in the early stages of arthropathy no ongoing symptoms are apparent. As the disease progresses, symptoms of pain, swelling, stiffness and decreased joint motion may be experienced. Ultimately the disease can progress to the point where the joint surface is so degraded that the joint no longer moves.

X-ray images of an elbow demonstrating bony cysts and destruction of the joint surface due to haemophilic arthropathy



DIAGNOSTIC TOOLS

Medical imaging plays an important role in the examination of arthropathic joints. Current diagnostic tools include plain film X-ray and MRI. The benefits of X-ray include low cost and ease of access. X-ray is a useful tool to monitor the appearance of bony surfaces and joint space over a period of time. It is not able to view the soft tissues of the joint effectively. MRI has long been considered the gold standard for joint imaging. It reveals much information about the bony and soft tissue structures. The main limitations of MRI are high cost, often long wait times, length of time taken for each imaging procedure and the need for the patient to remain still during this period. This last point is especially pertinent when considering the paediatric patient, who may not be willing to stay still for so long.

Ultrasound scanning has been an area of high interest in recent years in imaging of the haemophilic arthropathic joint. Most people know ultrasound scanning as the type of procedure used to look at a foetus in utero. Other uses for ultrasound include imaging of muscles, joints and tendons. Many physiotherapists will have some level of experience in using ultrasound to image the deep muscles of the abdomen and back. Ultrasound scanning has been proposed as an inexpensive adjunct imaging diagnostic tool that can be incorporated into everyday clinical practice.

HEAD-US

At WFH Congress earlier this year many of the physiotherapists from our national group attended an evening session on ultrasound. Carlo Martinoli, Associate Professor of Radiology at the University of Genoa, Italy, presented the session. Together with his team he has constructed a protocol known as HEAD-US (Haemophilia Early Arthropathy Detection with Ultrasound) for the easy assessment of haemophilic joints. Images are taken of the elbows, knees and ankles. For each joint the synovium, cartilage and bone is imaged and assessed. Ultrasound head placement is very prescriptive. For the elbow there are five positions, knee four and ankle five. An additive score is then calculated giving a numerical indication of joint disease activity, and disease damage.

In the current Australian system ultrasound scanning is generally performed by a sonographer. (A sonographer has completed a university degree on ultrasound scanning). However, it actually loses some of its value in the case of the haemophilic joint, when the patient needs to be referred to the sonographer, await the scan and then the results. Professor Martinoli suggests that physiotherapists are in a perfect position to take up this protocol for use as part of day to day practice.

Being so specific and prescriptive, the HEAD-US protocol is relatively easy to learn and apply. Professor Martinoli claims that once a clinician is proficient with its application, an assessment of all six joints can be completed within a few minutes. However, for a novice user the full assessment takes a significant length of time.

An advantage of incorporating ultrasound imaging into clinical practice would be the ability to see immediately whether the ultrasound images line up with the physical assessment findings. Evidence suggests that both clinicians and patients alike find it difficult to differentiate between arthropathic pain, and the pain caused by a minor bleed. The HEAD-US protocol is sensitive enough to pick up early changes in cartilage and subchondral surfaces below the cartilage. By imaging the bone, cartilage and synovium the clinician is in a much stronger position to able to say whether the symptoms that are being experienced are in keeping with an underlying joint pathology.

Professor Martinoli proposed that this would be a perfect protocol to integrate into annual joint health assessments. I am not aware of any of our national group physios who have taken him up on his recommendation. We as yet do not have the training or equipment in order to allow us to do this. We are as a group, however, very keen on further education in this area and on considering how it may play a role in our clinical practice.

So watch this space. In the future physios may have ultrasound scanning as another joint health assessment option.

A typical ultrasound scanner

SA

Sharon Caris is Executive Director, Haemophilia Foundation Australia

WHAT'S HAPPENING IN SOUTH AUSTRALIA?

Sharon Caris

GET TOGETHER
We have decided to have a get together for South Australians in the bleeding disorders community in early 2015. We hope this will be a chance for those who met for the first time at the recent Congress in Melbourne to catch up again, and of course for anyone living with a bleeding disorder to meet up with others in a similar situation and share their experiences.

Some people have suggested that as well as having the chance to socialise with one another, they would like to hear about new treatment developments and what is new in the care of people with bleeding disorders. We will plan for this, and would welcome your suggestions for any other topics that interest you.

Please let me know your ideas and suggestions on scaris@haemophilia.org.au or call HFA toll free 1800 807 173.

RED CAKE DAY
Thank you to everyone from South Australia who helped us to make Red Cake Day a success in October.

TEAM.FACTOR

For the third year a group of cyclists led by Dr Simon McRae and Andrew Atkins will ride as **Team.Factor** to take on the BUPA Challenge Tour on Friday 23 January 2015. The Tour will start in Glenelg and finish in Mount Barker in South Australia - over 150 km!

They will be fundraising for their favourite cause – Haemophilia Foundation Australia.

THE RIDE

The BUPA Challenge Ride is part of the Santos Tour Down Under in Adelaide, the first stop on the world elite cycling calendar. It gives regular cyclists the opportunity to ride the same Stage 4 route on the same day as the elite cyclists in the Tour Down Under.

It will also be a fantastic time for cycling enthusiasts to be part of the event that farewells Cadel Evans, the Australian cycling champion, who has announced that the 2015 Tour Downunder will be his final Union Cycliste Internationale World Tour event before he retires.

THE TEAM

Are you a keen and fit cyclist? In 2015 you too can come to South Australia and join Team.Factor in the BUPA Challenge Ride!

Headed by Royal Adelaide Hospital Haemophilia Centre Director Dr Simon McRae and haemophilia nurse Andrew Atkins, Team.Factor so far also includes haematologist Uwe Hahn, Hospital at Home nurse Dan Drake, and friend Phil Shaw from Shaw Family Vintners. They are eager to have other riders from around Australia to join them in the Team.Factor team.

Worried that you are not fit enough for the full ride? You do have the option of joining at later starting points and don't have to do the entire distance. Team.Factor encourages you to give it a go. "Even though it's timed, it's not a race, but a charity/fun ride," says Andrew Atkins, "and everyone rides at their own pace."

To join Team.Factor all you need to do is:

- Register as an individual at www.tourdownunder.com.au/individual-registration.htm. You can register until **5pm ACST on Wednesday 14 January 2015**.
- Email your details to Natashia Coco at HFA - ncoco@haemophilia.org.au
- We can add you to the Team.Factor fundraising page.

SUPPORT TEAM.FACTOR!

We are calling on all South Australians to come and cheer the team on at key spots in Glenelg, Willunga, Mount Compass, Macclesfield and the finish line at Mount Barker.

Contact Natashia Coco at HFA if you would like to be part of Team.Factor support at the event – email her at ncoco@haemophilia.org.au or phone 1800 807 173.

You can also support Team.Factor on https://give.everydayhero.com/au/team-factor-1.

Simon McRae, Dan Drake and Andrew Atkins in their Team.Factor shirts with SA supporter Paul Bonner

Team.Factor members Andrew Atkins, Dan Drake, Simon McRae and Uwe Hahn

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia

YOUTH UPDATE

Hannah Opeskin

Now that the State Foundations' family and community camps have concluded for 2014 and Christmas is almost around the corner, I am looking forward to working on some new projects with our young people.

YOUTH WEEKEND

We are looking at options for a National Youth Weekend in 2015. The weekend will be fun, where you can meet other young people with bleeding disorders and siblings, and maybe even learn something! Are you interested in attending? If so, please email your details to me, Hannah, at hopeskin@haemophilia.org.au and we will contact you with more information once the specifics of the weekend are confirmed.

FACTORED IN

Recently we conducted a survey to assess what young people affected by bleeding disorders across Australia wanted from the website Factored In (factoredin.org.au).

As a result, we will be improving areas such as:

- Changing some main menu pages
- Creating a 'what's new on the web site' feed on the home page
- Much needed software updates.

I am excited to work with young people to help make Factored In an even more useful tool.

Join Factored In

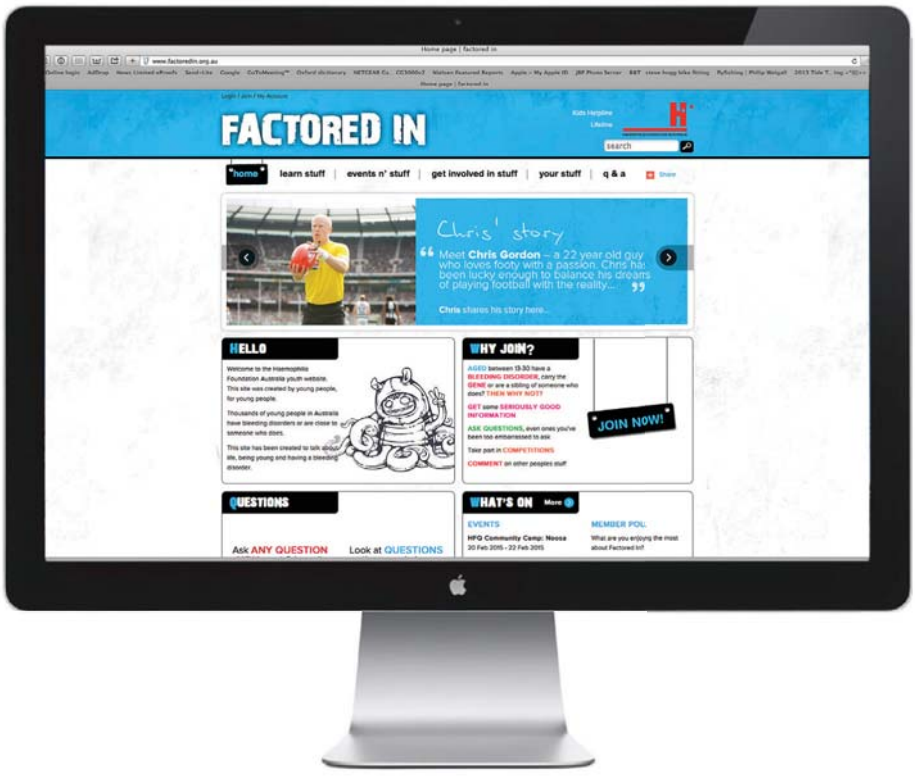
Signing up to Factored In is easy.

You must be aged between 13 and 30 years.

If you have a bleeding disorder, carry the gene or are a sibling of someone who does Factored In has a lot of helpful information.

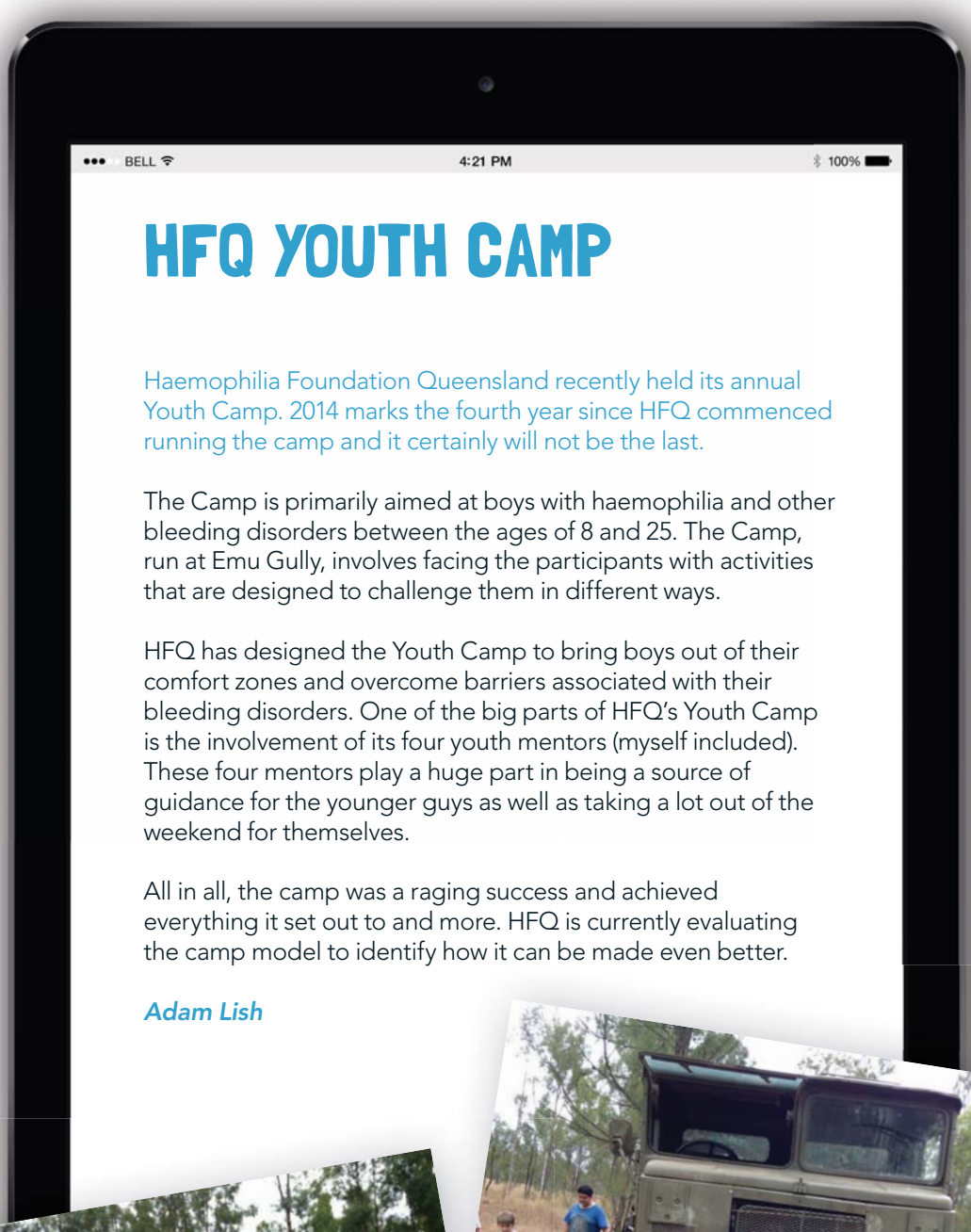
If you join, you can comment on other people's stories and questions and take part in competitions.

But even if you aren't a member, you can still read the information and stories and ask questions and have them answered by experts.



YOUTH NEWS

CATCH UP AT CAMP



CALENDAR

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

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

CORPORATE PARTNERS

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

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

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Season's Greetings

The staff and Council of HFA wish you the very best for a safe and happy festive season! Thank you for your invaluable support of people with bleeding disorders during 2014. We look forward to partnering with you again in 2015. Together, we can make a difference!

The HFA office will be closed from Wednesday 24 December 2014. The office will reopen fully on Monday 5 January 2015.

During that time if you have any queries or need to contact HFA, please note that messages left on the answering machine will be monitored. If you have an urgent matter please contact Sharon Caris on 0410 419 914.

 Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health which makes this publication possible.