

National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 191, September 2015

FACING THE FUTURE *Together*



HAEMOPHILIA AWARENESS WEEK 2015

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BECOME A MEMBER

Are you a member of your local Haemophilia Foundation?

JOIN TODAY!

Benefits include (varies between states/territories):

- **Support:** family camps, peer support groups and social functions
- **Information:** sessions, seminars, newsletters and use of resource library
- **Funding and Subsidies:** e.g. SOS Talisman/ MedicAlert subsidies, conference attendance subsidies
- **Representation** and entitlement to vote at the Annual General Meeting

For more information contact your local Foundation directly –

Haemophilia Foundation ACT (HFACT)

Ph: 0412 839 135
Email: president@hfact.org.au
Website: www.hfact.org.au

Haemophilia Foundation New South Wales (HFNSW)

Ph: 02 9249 7302
Email: coordinator@hfnsw.org.au
Website: www.hfnsw.org.au



Haemophilia Foundation Queensland (HFQ)

Ph: 07 3017 1778
Email: info@hfq.org.au
Website: www.hfq.org.au

Haemophilia Foundation South Australia (HFSA)

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Website: www.hfv.org.au

Haemophilia Foundation Western Australia (HFWA)

Ph: 08 9420 7294
Email: office@hfwa.org
Website: www.hfwa.org

Help improve the lives of people with a bleeding disorder and support **Red Cake Day** during **Haemophilia Awareness Week**



Red cakes can change lives! **It's true.**

They can. That's why HFA are calling on our friends and supporters to help us celebrate **Haemophilia Awareness Week** by taking part in **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 to raise funds and awareness about haemophilia, von Willebrand disorder and other bleeding disorders during the week of **11-17 October 2015**.

To order your free promotional items, download an order form from www.haemophilia.org.au or email donate@haemophilia.org.au

GET IN QUICK - STOCKS ARE LIMITED!

How can I get involved?

- Organise a **Red Cake Day** at your home, workplace, school, kinder or community group.
- Order free napkins, pens, tattoos, stickers and colouring sheets and pencils to make your **Red Cake Day** extra special!
- Display free posters, postcards and newsletters and raise awareness about haemophilia, von Willebrand disorder and other bleeding disorders.
- Tell all your friends, family and colleagues about **Haemophilia Awareness Week** and encourage them to hold their own **Red Cake Day** event!



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)



For more information on Haemophilia Awareness Week and Red Cake Day, visit www.haemophilia.org.au/redcakeday or call HFA on 1800 807 173



RED CAKE DAY

DURING

HAEMOPHILIA AWARENESS WEEK

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 to raise awareness about haemophilia, von Willebrand disorder and related inherited bleeding disorders throughout Australia during the week of **11-17 October 2015**.

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

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

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

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



To order your free promotional items, visit www.haemophilia.org.au/redcakeday.



FOR MORE INFORMATION

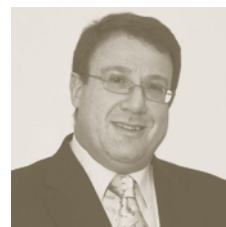
visit www.haemophilia.org.au/redcakeday
call HFA on 1800 807 173
email Natashia.ncoco@haemophilia.org.au.



Like HFA on Facebook
www.facebook.com/RedCakeDay



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



FROM THE PRESIDENT

Gavin Finkelstein

“Our Australia/New Zealand conferences are so valuable. They are great to meet, share ideas and socialize together.”

UPCOMING CONFERENCE

As I thought about the things to mention in this publication I was mindful that I will be seeing some of you at the upcoming 17th Australian & New Zealand Conference on haemophilia and related bleeding disorders quite soon after you receive it.

I am looking forward to the Conference, yet it doesn't seem so long ago that we came together for the WFH 2014 World Congress in Melbourne. Our Australia/New Zealand conferences and the World Congress are very different from one another, but they each offer people with bleeding disorders something special. For me, the smaller local conferences we have in Australia are great because they bring people from different parts of Australia (and New Zealand) and we can concentrate on local issues. Of course we can learn from the overseas experiences of others, and we can measure how well we are going in terms of treatment and care standards, but it is good to stop and think about how things are going here in Australia.

KEEPING IN TOUCH

It is a big country, and people with bleeding disorders are distributed widely around the country just like the general population. Some people with bleeding disorders don't have a chance to meet others because they live in rural or remote areas. But even for those of us who live in cities, we may not see each other very often. We did at one time, when we spent more time at the hospital. Home therapy revolutionized our treatment, and home delivery has made it very convenient. How often do you visit your Haemophilia Centre? We do need to keep in touch with our treatment team in case issues arise or things change. I know how easily time slips by. You might be thinking it is time to set up a review appointment with the Haemophilia Centre, then before you know it, you get busy, time passes and you still haven't made that appointment. It is important for all sorts of reasons.

CONNECTING WITH OTHERS

As I mentioned above, with home therapy and prophylaxis, many of us don't need to go to our Haemophilia Centre as often as before. This means we don't see our peers as often. This is why I think our Australia/New Zealand conferences are so valuable. They are great to meet, share ideas and socialize together as well as check we have best practice treatment and care and be on the look-out for new treatments that are around the corner. We already have longer acting clotting factors registered for use in Australia but not yet funded. It is important that we are well educated about all treatment products so we can make a good decision with our doctors about which products we should use.

CONFERENCE FUNDING

It may not be too late at the HFA end yet, so if you can make quick plans, you might still be able to get to the Gold Coast! If you would need help with funding, I suggest you call HFA immediately on 03 9885 7800 as there still might be some financial assistance available.

ONLINE PRESENTATIONS

We will publish the speakers' presentations on the website in the months following the Conference so if you are not there in person we hope you will be able to follow some of the sessions afterwards.

HEP C TREATMENT

The news on the hepatitis C treatment front is very frustrating. Generally when the Public Benefits Advisory Committee recommends a medicine for listing the medicine becomes available to Australians at a subsidised rate. Although PBAC has approved the new hepatitis C treatments for certain indications, they are still not available and we are hearing about the desperation of people who need treatment urgently. We will not rest until everyone gets the treatment they need. #

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



1 - 3 OCTOBER 2015 • GOLD COAST

2015

The 17th Australian & New Zealand Conference on haemophilia & related bleeding disorders will be held on the Gold Coast from 1-3 October 2015. The theme for the conference is "Facing the Future Together"

GOLD COAST CONFERENCE

REGISTER NOW

It's not too late to register for the Conference – register online at <https://www.secureregistrations.com/HFA2015/>

or

download a registration form at www.haemophilia.org.au/conferences.

Funding for community representatives may still be available! – call HFA urgently

PROGRAM

For current updates visit www.haemophilia.org.au/conferences.

The program covers topics such as:

- Comprehensive care
- Von Willebrand disease
- Mild haemophilia
- Hepatitis C
- Inhibitors
- Youth Q&A panel with engaging topics
- HIV
- Approaching pain
- Making informed family planning decisions and genetic counselling
- Mental health
- Getting older
- Being active
- Women and bleeding disorders
- New therapies including longer acting factor

SATURDAY AFTERNOON WORKSHOPS

There are 3 choices for Saturday afternoon from 3pm. These are ticketed events and bookings must be made. All programs are included part of your conference registration.

**Mindfulness ~
Dr Ira Van Der
Steenstraten
1515-1615**

**Catch up and chill
out afternoon tea
1500-1630**

**Viewing of AFL
Grand Final
1500-1800**

OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

Health Professionals Meetings

Annual meetings of the Meetings of Australian Haemophilia Centre Directors' Organisation, Australian Haemophilia Nurses' Group, Australian Haemophilia Social Workers' and Counsellors' Group, Australian & New Zealand Physiotherapy Haemophilia Group and the ABDR Data Managers Group will be held on Thursday 1 October 2015.

Youth Social Function

After the Welcome & Exhibition Opening on Thursday 1 October, young people are invited to a **VIP meet & mingle** social function. This will be onsite and will be free of charge. This will be a chance for young people to meet others and connect before the Conference program starts. Tickets will be issued to Youth Delegates with their registration lanyards.

Remembrance Service

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

Conference Dinner

Join your fellow delegates for the Conference Dinner onsite on the Friday evening. The dinner will be informal and fun and it is a great chance for you to talk, share and meet others. Tickets are \$35 and include food and beverages. Dinner tickets must be purchased in advance - no tickets will be available during the conference or on the night. Sit where you prefer on the night.

A Men's Breakfast and Women's Breakfast will be held on Saturday 3 October.

Come along to hear an interesting speaker and share your ideas and experiences with other men or women!

FOR MORE INFORMATION

Visit the conference website
www.haemophilia.org.au/conferences #



QT Hotel – the conference venue
Photos: QT Hotel

HEP C NEWS

Several new generation direct acting antiviral (DAA) hepatitis C treatments have now been approved for use in Australia, but Australia still lags behind the rest of the world in affordable access to the treatments.

NEW APPROVALS

We were pleased that in July 2015 the Pharmaceutical Benefits Advisory Committee (PBAC) recommended adding **Viekira PAK®** to the Pharmaceutical Benefits Scheme (PBS) for the **treatment of chronic hepatitis C genotype 1**.

In line with the new process to speed up the approval process, the new treatments have been going before the Therapeutic Goods Administration (TGA) to be approved for use in Australia at the same time as the Pharmaceutical Benefits Advisory Committee (PBAC) for listing on the Pharmaceutical Benefits Scheme (PBS). Listing these new treatments on the PBS would mean they are subsidised by government and would allow Australians to access them at an affordable cost.

Another treatment for hepatitis C, a combination of simeprevir/sofosbuvir, also went before the PBAC in July 2015, but is waiting on TGA approval for the PBAC outcome to be made public.

HFA made a substantial submission to the PBAC in support of these treatments, including comments of community members from HFA surveys.

GREAT NEED FOR EFFECTIVE NEW TREATMENTS

The PBAC undertook a thorough evaluation of treatments and were clear that all the approved new treatments for hepatitis C are very effective - both Viekira PAK and the other hepatitis C treatments approved in March 2015. They recognised that there is a high clinical need for all-oral interferon-free hepatitis C treatments to be made available on the PBS.

Viekira PAK® (paritaprevir with ritonavir, ombitasvir, and dasabuvir, with or without ribavirin) would be another option for treating genotype 1 – as effective as treatment with Harvoni® (ledipasvir with sofosbuvir).

These new all-oral treatments would be easier to manage, and the PBAC recommended listing them in the General Schedule so that prescribing these treatments would no longer be limited to specialist clinics. Infrastructure would need to be built to support this but in the longer term it would mean wider access to treatment, including in regional areas.

ACCESS DELAYS

However, once again the PBAC did not accept the proposed treatment prices.

There are now four new hepatitis C treatment combinations that have been approved by the PBAC and none are available yet on the PBS. These treatments are already available in many other countries.

“ My community members with bleeding disorders and hepatitis C have been waiting for these treatments for too long. ”



“Access to these treatments is critical for Australians with hepatitis C. My community members with bleeding disorders and hepatitis C have been waiting for these treatments for too long. Every delay puts their health and their lives more at risk,” said Gavin Finkelstein, HFA President, in a recent media release. “Government funding is needed urgently to list these medicines on the PBS. These treatments can cure hepatitis C – and if they are not on the PBS, these treatments are just not affordable for most Australians with hepatitis C.”

The next step in the process is for the Australian government to consider the PBAC recommendations and make decisions about funding. It is important that the cost of these drugs is negotiated successfully with the pharmaceutical companies without further delay.

HFA is continuing to make representation to government about access to these treatments for people with bleeding disorders.

AND IF YOU HAVE HEP C?

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

- Make sure you have your liver health checked regularly
- If you don't know where to start, ask your Haemophilia Centre for a referral
- Stay in touch with your hepatitis clinic about what's new
- 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
- And for comprehensive care, let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop. **H**

NEW HEP C TREATMENTS APPROVED BY PBAC IN 2015

- Daclatasvir (Daklinza®) in combination with Sofosbuvir (Sovaldi®)
- Ledipasvir with sofosbuvir (Harvoni®)
- Sofosbuvir (Sovaldi®)
- Viekira PAK® (paritaprevir with ritonavir, ombitasvir, and dasabuvir, with or without ribavirin)

WORLD HEPATITIS DAY

World Hepatitis Day was marked globally on 28 July 2015.

As a Partner in the national World Hepatitis Day Campaign, HFA worked with Hepatitis Australia and State and Territory Foundations to target the national awareness campaign to the bleeding disorders community and is committed to making a difference on hepatitis C in Australia.

In 2015 we took the key messages recommended for the bleeding disorders community by specialist health professionals and transformed them into a national social media campaign.

The national theme was tweaked to read: **It's #timeforaction! Know if you were exposed to hep C; get tested; have a liver check; ask about treatment.**

Social media messages were released daily via HFA and Foundation Facebook pages and Twitter in the lead-up to World Hepatitis Day.

#TIMEFORACTION SOCIAL MEDIA CAMPAIGN

Hep C and liver health are a big issue for the bleeding disorders community. We shared 1 tip a day leading up to World Hepatitis Day on July 28 on how to look after your liver.

Tip 1: Many people with bleeding disorders are affected with hep C but do you know your hep C status? If you used factor before 1990 - even as a baby - you could be at risk.

It's time for action! If you don't know whether you have hep C or not, get tested now!

Tip 2: If you have hep C and haven't had a liver health test in the past 2 years, it's time to get your liver checked now. Have your liver checked regularly.

Tip 3: Did you know that if you need hep C treatment you need a liver health assessment first? Get a liver health check now. If you don't know where to start, talk to your Haemophilia Centre about a referral.

Tip 4: If you have hep C, let your Haemophilia Centre know about your liver test results and treatment.

Tip 5: If you have hep C, stay in touch with your hepatitis clinic for latest news and updates.

Tip 6: Does someone in your family have hep C? Talk to them about looking after their liver!

Here are some easy recipes for a happier healthier liver! www.loveyourliver.com.au/entrees-and-light-meals

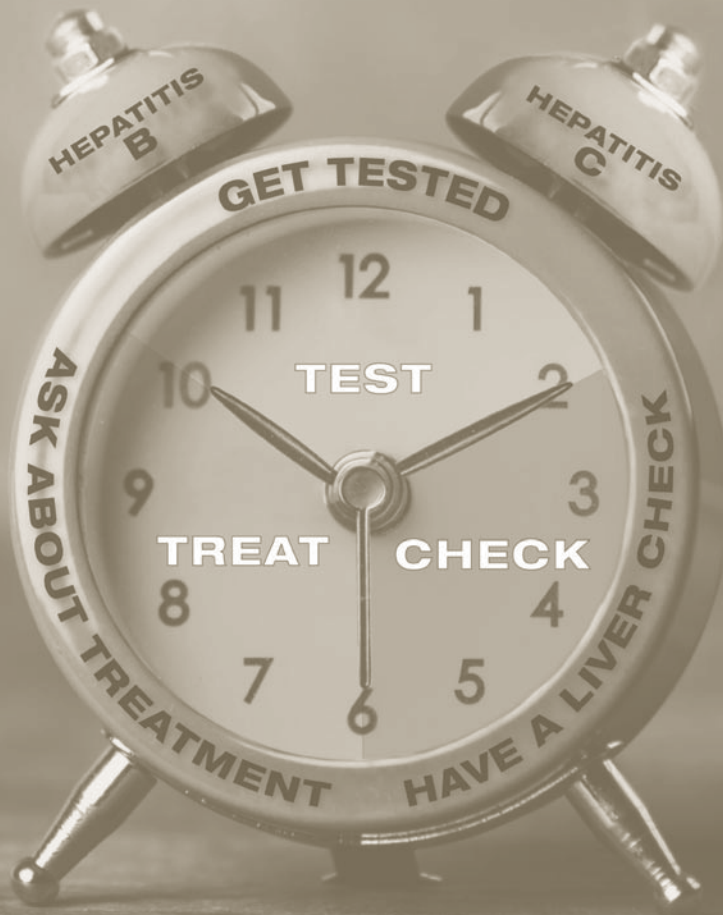
Tip 7: [World Hepatitis Day] It's #timeforaction! Know if you were exposed to hep C; get tested; have a liver check; ask about treatment.

Find out more

Love your liver - for information on World Hepatitis Day, liver health checks, liver-friendly recipes - www.loveyourliver.com.au



TIME FOR ACTION



WORLD HEPATITIS DAY

hepatitis
australia

National Infoline: 1800 437 222
1800 HEP ABC

 www.facebook.com/loveyourliver.com.au
 www.twitter.com/love_your_liver

 LOVE YOUR
LIVER
www.loveyourliver.com.au

ONLINE RESOURCES

Several national resources were developed by Hepatitis Australia to support the campaign:

- The **#timeforaction** video – www.tinyurl.com/timeforaction-video
- A video on liver health checks and fibroscan featuring Grenville, who has hep C, and Assoc Prof Simone Strasser, a hepatitis specialist at the Royal Prince Alfred Hospital - www.tinyurl.com/liverhealthchecks-video

- **Together we can see our future** book of personal stories (includes Australians with bleeding disorders, Ian Pengelly and Malcolm Cockrum) - www.hepatitisaustralia.com/together-we-can

State/territory hepatitis organisations also ran local activities.

MORE INFORMATION

World Hepatitis Day page - www.loveyourliver.com.au/worldhepatitiday #

NEW HEP C PERSONAL STORIES BOOK

In the compelling new book *Together we can see our future*, 29 Australians have come together to tell their story of living with hep C.

Among the individual accounts are the personal stories of two authors who have bleeding disorders: Ian Pengelly, from Queensland, who has von Willebrand disease, and Malcolm Cockrum, from NSW, who has haemophilia.

Every story in the book gives a different perspective, and includes comments from friends and relatives. Ian's story, for example, is supported with a statement by his uncle, Senator Ian Macdonald. Some of the authors have had successful treatment, while others have not been so lucky, and some are still waiting for final results. But they all have in common their courage, their resilience, and their hope for a better future.

Hepatitis Australia published the book and launched it in Canberra in June 2015.



Sharon Caris, HFA, and Ian Pengelly at the launch
Photo: Hepatitis Australia

Sharon Caris, HFA Executive Director, caught up with Ian Pengelly at the launch.

"The book includes many inspiring personal stories. Meeting Ian made me realise what a remarkable journey the authors have travelled in writing their story.

Their stories make us hope that things will improve for people living with hepatitis C in the very near future," said Sharon.

WHERE TO GET A COPY

You can download or read the book online at www.hepatitisaustralia.com/together-we-can.

Hardbound copies will also be available at the HFA stand in the trade exhibition at the 2015 Gold Coast Conference. #

This article is adapted with permission from *Bloodline*, the newsletter of the Haemophilia Foundation of New Zealand Inc (www.haemophilia.org.nz), vol. 43, no. 2, June 2015

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

CALMING THE BUSY MIND

Sarah Elliott

Coping with the demands of living with a bleeding disorder can be very stressful and cause much anxiety at different times in you or your child's life. These concerns can get your 'chatty brain' going 100 miles per hour, and you may find it hard to concentrate or think clearly as your talkative inner voice works overtime and accentuates all your concerns, stressors and fears.

Each time you contemplate or worry over small details your body produces a surge of stress hormones which is bad for all elements of your wellbeing and causes clouded thought which often leads to further anxiety and making mistakes.

Although some stress is 'normal' and even important for us, there are times when stress builds up and is detrimental to our health.

Below are some ways to overcome and deal with stress and anxiety, as well as to calm and centre yourself. Try some of these techniques to find which ones work best for you:

Me time: Value yourself by making time for things you enjoy such as reading, listening to music and getting a massage.

Conscious relaxation: Things like meditation, yoga, mindfulness, breathing techniques and positive affirmations can help to quieten your mind and find peace. They can help you control and decrease the stress in your life and simultaneously increase your capacity for inner growth.

Exercise: Exercise releases endorphins and makes you feel good, it also helps you sleep better and maintain healthy body weight and strength. In particular, rhythmic exercise such as swimming, cycling or running is calming. Be careful though as when you are stressed as it is often a time for increased accidents as your concentration is lacking. Also make sure your exercise is appropriate for you and your bleeding disorder.

Interaction with animals: Animals can help you calm down and take your mind off a problem.

Manage your time well: A common cause of stress is having too much to do and too little time in which to do it, but you have more time than you think. Write priority lists, learn to say "No" and make limits on what you can and can't do.

Remove harmful toxins: Limit stimulants such as alcohol, caffeine, nicotine and even sugar as these can aggravate and trigger panic attacks.

Build a relationship with the environment: Many of us feel more connected and calm when we are out in nature. Life's problems seem to diminish when surrounded by magnificent mountains or clear blue lakes. Visiting places of significance in your life can also revitalise you.

Sleep: When you are stressed your body needs additional sleep – but when you are stressed it is always harder to sleep! Rather than relying on medication, your aim should be to maximise your relaxation before going to sleep. Make sure that your bedroom is a tranquil oasis with no reminders of the things that cause you to worry and have a routine time to go to sleep and wake up.

Relationships: We can reduce stress by making time for important people in our life and eliminating people who drain our energy and time. The people who know us well can help us put things in perspective.

Spiritual connectedness: Whether it be a religion, or a connection to a higher power this can bring comfort or security, a place to belong, a feeling that

not EVERYTHING is on your shoulders or up to you to control. Connecting with your culture can also uplift your spirit and increase your resilience.

Healthy diet: Eat well-balanced healthy meals regularly as it helps to balance your mind and thoughts and can make you more rational. Do not skip any meals just cause you are 'too busy' as this will only add to stress or agitation down the track, and remember to keep healthy energy boosting snacks on hand in stressful times.

Take control: Consider what you can and can't control – let go of what you can't control and accept it. Be smart about what you can control. Try writing down your problems and stress triggers and finding solutions to these. Find out what decreases your stress and put these into action ASAP.

Connect to wider society: To fit in or belong, to be a part of something bigger and to connect to others socially is vitally important. Get involved in different social groups or volunteer until you find something you really enjoy and where you feel accepted and comfortable.

Welcome humour

Ask for help when needed: Sometimes we are so deep into coping with our lives and what is happening that we don't recognise when we need to ask for help. Reach out - there are people out there who can help you to find ways and mechanisms to reduce stress and anxiety. There are people willing to share some of the load and help you through if you let them.

It is so important to recognise your own stress cycle, acknowledge and understand what causes stress, and trial different techniques to see what reduces your stress. Try to be proactive and preventative in caring for your mind by using positive strategies to build your resilience, support systems and happiness in times when everything is good; instead of just waiting until you are stressed out.

Think of it like prophylaxis – taking your factor preventatively reduces the chance of getting a bleed; it is the same with your mental wellbeing.

If you would like more information about reducing stress, anxiety and your 'chatty brain' then contact your Haemophilia Social Worker or Counsellor. They can help to support or refer you on to someone who can. ■

MYABDR UPDATE



From the HFA and National Blood Authority
MyABDR Team

WHAT'S NEW?

A new version of the MyABDR app was released in August 2015, bringing you more improvements and features:

- Faster synchronisation
- Access to your HTC contacts and Help pages without needing a data connection
- Bug fixes to prevent any duplicate stock and treatment entries, and to tweak the time 'since last MyABDR recorded treatment' timer and the default treatment day.

These changes are all in response to user feedback over the last few months.

Make sure you update your MyABDR app to take advantage of these new enhancements and fixes!

NEED HELP?

Don't hesitate to contact the MyABDR Support team with any queries. Meghan, Danny, Lachlan or Rebecca are available 24/7 and will be happy to assist you.

T: 13 000 BLOOD / 13 000 25663

E: myabdr@blood.gov.au

Available 24 hrs a day, 7 days a week.

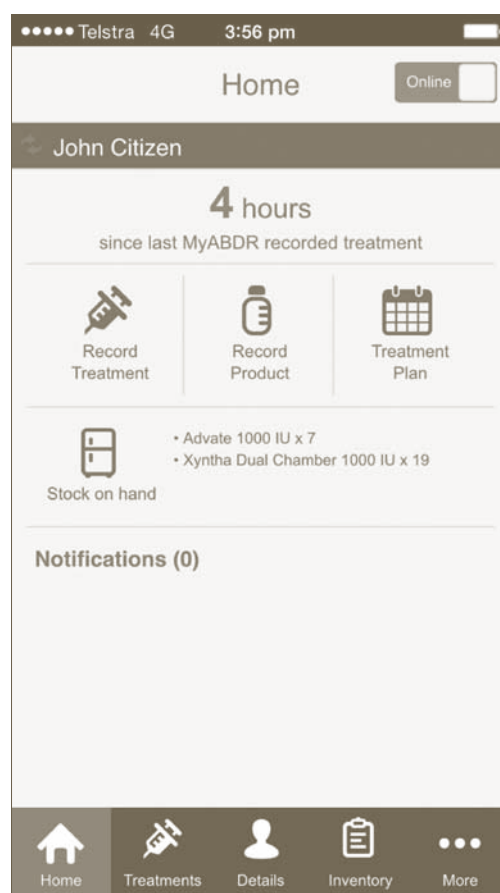
MYABDR AT THE CONFERENCE

Look out for the National Blood Authority booth in the exhibition at the 2015 Gold Coast Conference in October.

The team will be keen to catch up with you about MyABDR to fill you in on the latest developments and what is planned, get your feedback and suggestions, and to help you with any queries.

MYABDR SURVEY

Thank you to all those who replied to the MyABDR user survey held in July 2015. We had a wonderful response rate and will use all your feedback and comments to develop future enhancements for MyABDR. We are analysing the data and will provide a summary feedback and what we are actioning from the feedback in coming weeks.



MyABDR FUTURE PLANS

The next release of MyABDR will be available in mid-October, and will include the ability for users to request their own updated emergency card and whether they would like it sent to their Haemophilia Treatment Centre or direct to their nominated delivery address.

This update in October will also further streamline the treatment recording process to make it even easier to add in treatments. ■

TAKING PART IN MARKET RESEARCH

Suzanne O'Callaghan

With so many new clotting factor products now coming on the market, you may have noticed that market research companies are actively looking for patients and parents/carers to interview or survey about their bleeding disorder or their treatment. But is it a good idea to take part?

WHAT ARE THE PROS AND CONS?

Taking part in market research studies can be valuable for you and for others. In Australia research has a big influence on decisions about health services, treatment and care. If you participate in research, you can have your say on treatments, how they are packaged or presented, and their patient support programs, when you or others might be using them in the future.

But before you take part in a market research study, it is important to know more about its benefits and risks for you and whether it will have any impact on your health or privacy. Also, bear in mind that the laws and standards for relationships between pharmaceutical companies and community members are quite strict in Australia and different to other countries. For example, in Australia it is not permitted for prescription products to be promoted to the public, but this is quite acceptable in the U.S. This means that market research questions in Australia must be careful not to promote a particular product.

HFA regularly reviews market research studies before we promote them on the HFA web site. We have a list of questions to check they are meeting Australian standards and ask to look at their interview or survey questions. Many Australian market researchers belong to professional associations in Australia and follow their codes of practice and also follow the Medicines Australia Code of Conduct, so for some this is just a formality.

Examples of what we ask or check:

- We ask whether they pass the research participant's personal information on to the pharmaceutical company (not OK in Australia!) or another mailing list (only OK if the participant has given permission – for example, if you agree to take part in further surveys).

- We check whether an "online support group" is actually market research capturing people's comments and experiences for a pharmaceutical company.
- We also check to see whether the questions are too delving or intrusive and might be distressing or trying to encourage a person to seek a specific product.

SOME POINTERS

If you are interested in taking part in a market research study:

- Check the HFA web site under **Bleeding disorders > Participating in research** to see whether the study is listed (NB - we only list studies researchers have sent to us)
- HFA doesn't permit researchers to recruit participants by posting directly on the HFA Facebook page so beware of answering any research requests posted there by researchers who are not from HFA!
- Ask the researchers more about the study and how they will protect your privacy – there are a list of useful questions on the HFA web site
- You might also find it useful to discuss the market research with someone independent of the study, eg a member of your Haemophilia Centre team or your Haemophilia Foundation or your GP.

And if you have any queries about a research study, feel free to contact Suzanne O'Callaghan at HFA – socallaghan@haemophilia.org.au or T: 1800 807 173. **#**

MUSCULOSKELETAL

Cameron Cramey

14th WFH International Musculoskeletal Congress, Belfast, Northern Ireland, 7-10 May 2015

Belfast, Northern Ireland, hosted the 14th International Musculoskeletal Congress over four days in May this year. Attended by over 300 delegates from more than 40 different countries this Congress provides an opportunity for health professionals to learn, listen and debate current best practice and future research directions relevant to haemophilia.

Nestled along the banks of the River Lagan, perhaps most famous for being the location for the construction of *The Titanic*, the Hilton Hotel was the venue for this year's Congress. With an emphasis on 'best available evidence', the Congress covered wide ranging musculoskeletal issues related to haemophilia. Some of the highlights from the Congress included discussion about the ever expanding use of 'outcome measures'; the developing use of ultra-sound in haemophilia; some new research around individual variations in joint bleeding patterns; the safety of radio-active synovectomy; and some lively debate about the role of joint replacement surgery for ankle haemarthrosis.

MEASURING HEALTH OUTCOMES

Outcome measures are regularly used by health professionals to help monitor how people are managing or coping with their haemophilia. Some measures you may be familiar with include the Haemophilia Joint Health Score (HJHS), self-reported questionnaires, and regular imaging including x-ray and MRI. We heard from a range of speakers discussing the pros and cons of a wide range of tools used as outcome measures. It was agreed that the use of these measures play an important role in optimising the management and quality of life for people with haemophilia. So although they can be pesky, taking the time to complete questionnaires and doing annual HJHS with your physiotherapists is valuable for both you and your haemophilia treatment team.

Many of you may be used to having regular x-ray (or MRI) to help monitor the health of your joints. Several Haemophilia Centres around the world are now

starting to incorporate the use of ultra-sound as part of their annual patient reviews to perform this valuable monitoring. We heard from several speakers who discussed the reliability and usefulness of this relatively affordable and quick screening tool to assist with: joint health monitoring; and management of acute or chronic joint bleeds and synovitis. It appears to be a positive development to supplement existing management approaches and some of you may begin to see your Haemophilia Treatment Centre (HTC) beginning to use more ultra-sound to aid in the management of your haemophilia.

JOINT ISSUES

We know that people with haemophilia who have recurrent joint bleeds are susceptible to developing early joint damage known as haemarthrosis. Why some people with haemophilia are more affected than others is not really known, however some developing research coming out of the Netherlands suggests that this variation could be attributable to how each person's body responds to the inflammatory process that occurs during a joint bleed. Research is currently underway to further understand this inflammatory response to see if more targeted treatment could be developed. But in the meantime, remember to contact your HTC for review following any joint or muscle bleed.

Sometimes people with haemophilia suffer from recurrent joint bleeds or ongoing joint swelling (without active bleeding) due to inflammation and thickening of their joint lining (synovium). In particularly persistent cases removal of the synovium is required (synovectomy). Radiosynovectomy involves the injection of a radio-active material (different material used depending on which country you live in) to remove the synovium rather than doing it surgically. Despite debate amongst the European and American HTCs about which material is best to use, the consensus amongst all centres is that the use of radiosynovectomy is considered safe and a good alternative to surgical synovectomy.

ANKLE DEBATES

Many of us will know someone with haemophilia who has had an ankle fusion to help control bleeding or pain.

CONGRESS REPORT

In recent times ankle replacements have emerged as an option to help control bleeds and pain, with the aim of also optimising function and preserving movement. Due to the relatively recent development of ankle replacement surgery, not much is known about the long term results of this type of surgery. There was much lively debate amongst the orthopaedic surgeons who attended the Musculoskeletal Congress over the pros and cons of ankle replacement compared with ankle fusion. Emerging evidence suggests that both provide good patient outcomes and the decision for selecting one over the other should be discussed with the patient and their HTC team.

The Congress concluded with a farewell dinner and drinks at the Titanic Belfast with a chance to wander through the Titanic museum; a fitting way to end an informative four days in Belfast. A big thank you to HFA for providing me with this valuable learning experience and opportunity to meet and discuss current management practice in HTCs from across the world. Ongoing research will hopefully allow us to continue to improve our management of the musculoskeletal issues associated with haemophilia, and participation in these international conferences will help ensure Australian HTCs remain up to date with international best practice. ■

Australian Haemophilia Physiotherapists:
(left-to-right) Cameron Cramey and Abi Polus



Session at the Musculoskeletal Congress



Reliving the Titanic in Belfast

Colleen McKay is Manager, Outreach Services, Haemophilia Foundation of New Zealand Inc.

SIBLINGS – BEST OF FRIENDS AND RIVALS

Colleen McKay

If you have children, you know that maintaining peace in your household can be difficult. One minute your children are getting along and the next minute they're enemies. Knowing when and how to intervene can make a difference in how well your children relate to each other.

In families each child is an individual and their needs differ. If there is one or more members in a family with a bleeding disorder such as haemophilia or von Willebrand Disease (VWD), the entire family is affected in some way or another. This is why open communication with each and every member of the family, as well as listening to how each person feels about what is going on with the bleeding disorder, should be a high priority.

The first part of this article focuses on the common feelings and behaviours of siblings with bleeding disorders and tips for the parent to deal with them. The second part is more general and deals with strategies for understanding and dealing with sibling rivalry.

WHEN A SIBLING HAS A BLEEDING DISORDER

In families each child is an individual and their needs differ. The child with a bleeding disorder can often require greater time and attention from their parents. Other children in the family can come to resent the time and attention that is given to the child with the bleeding disorder. If the bleeding disorder becomes the focus of your family, siblings may feel left out and even guilty that they are healthy.

Two things are certain. Firstly, the child with the bleeding disorder must have his / her needs met, and secondly, the other children are entitled to your love and attention also.

Possible feelings and behaviours of siblings of children with bleeding disorders:

- Jealous about the attention that their sibling gets
- Angry that no-one pays any attention to them
- Feel neglected and left out
- Feel guilty because of the feelings of resentment, jealousy, and anger
- Resort to bad behaviour in order to get attention; negative attention can feel better than no attention at all
- Worried about their sibling and scared that they might lose their sibling
- Feel isolated and alone, and unable to express their own feelings
- Minimise their own needs, because they do not wish to bother their parents
- Feel empathy towards their sibling, are caring and concerned
- Over-protective and look after their sibling.

Helpful tips for parents to help siblings deal with these feelings and behaviours, and to manage the conflicting demands:

- Be open and honest with siblings about the bleeding disorder and any complications
- Provide age-appropriate information about their sibling's bleeding disorder
- Encourage siblings to be involved in treatment
- Set aside time for talking about their feelings can help siblings to build coping skills and know that their feelings are acceptable.
- Recognise the needs of all of your children, including those who do not have a bleeding disorder.
- Value each child and spend individual, special time with each of your children.
- Accept that you might not be able to be completely even-handed – one child might need more of your time.
- Expectations regarding abilities, interests, and aptitude should be consistent for all of your children.
- Feelings and accomplishments of siblings should be respected and praised.
- Discipline must be safe and appropriate for all of your children.



- Avoid the temptation to treat the child with a bleeding disorder differently than you treat your other children.
- Remember to take care of yourself too so that you don't become too exhausted. For example, plan with your partner to take some time out for yourself. Sole parents need to ensure they have support from parents, other family, friends and neighbours to enable this to occur.

SIBLING RIVALRY

Because brothers and sisters live closely together within the family and affect each other's lives, they often get angry and frustrated with each other. They sometimes compare with each other and can become jealous, bossy, resentful or competitive. They often test out their strengths and weaknesses on each other. These tensions are called sibling rivalry.

The biggest problem faced by young siblings is that they have to share the most important person/s in their lives: their parents.

International research shows that serious sibling rivalry happens less often in families where:

- Physical aggression and violence are not acceptable behaviour,
- Children are shown good anger management and problem-solving skills by adults
- Family members have good times and fun together.

Sibling rivalry is very common, but it can still be very tiring and difficult to put up with for the parents and the rest of the family. As a parent there are a number of things that you can do to at least minimise the conflict.

The most important one is to accept that it is a perfectly healthy process during which both children are learning a lot of important skills about getting along with other people. Everything you do should be aimed at supporting and enhancing that process.

There are good things about sibling rivalry.

As the children in a family discover how to get along together and grow up together they will learn very important and helpful life skills. Skills such as:

- How to understand, respect and consider another person's needs and ideas
- Ways to compromise, negotiate and problem-solve with others
- Ways to express and safely manage angry feelings
- How to forgive and patch things up after anger.

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These are great skills to have. It is important that children have the opportunity to learn them and have opportunities to practice them in a safe environment.

Tips for parents to deal with sibling rivalry:

- Try not to get involved – as far as possible encourage them to sort out their own differences and get along together. Mediate between them only if it's really necessary.
- If you do have to step in, separate them until things have calmed down. Don't focus on who is to blame. Work with the children on ways of resolving the dispute; try to find a win/win solution.
- Acknowledge the resentment or anger, e.g., 'I know that you feel very angry with Anne, but you can't hit her with a stick.'

- Help them to learn not to expect everyone to always do or see things the way they do. Teach them to respect others. Everyone is different.

- Let them express angry feelings in safe ways. Teach them that it's OK to feel anger but hurting others or things when you are angry is never OK.
- Manage your own anger well. If anger management is a problem for you, seek help so that you can role model good anger management strategies.
- Teach forgiveness. Learning to patch things up and forgive is a life skill.
- Set ground rules for acceptable behaviour. Get the children involved on working out the

ground rules. Keep them simple. Write them down and stick them on the fridge door or family notice board.

- Praise good behaviour. Let them know that it's great when they get along well together and enjoy each other's company.
- Don't make comparisons – each child is unique and resents being compared to another. Never show one child special treatment.
- Make time to have fun together as a family. Find things to do that everyone enjoys, even just simple things. Making memories is something special that siblings can share again together in the future. Celebrate special events. #

NEW NATIONAL WEBSITE PROJECT

Haemophilia Foundation Australia is embarking on a new National Website project to re-develop the website www.haemophilia.org.au and the youth website www.factoredin.org.au.

This is a very exciting initiative for HFA and State/Territory Foundations and is the result of several years of concept development with HFA Council: with the agreement of State/Territory Foundations this project will also result in new websites for State/Territory Foundations.

The aim of this project is for State and Territory Foundations to share a standard content management system with HFA (structure and web site administration) and for all Foundations to have consistent and professional branding, while maintaining their own web address and identity (ie, they will look similar but not the same). They will be able to update information and send out email newsletters on local events and activities themselves. Email newsletter databases for each Foundation will be private, accessible only by that Foundation, and protected with world best practice

security. Content developed by HFA, such as information about bleeding disorders, or news items on national issues, will be shared seamlessly with the State/Territory Foundation sites.

This would also mean all the complexities of making sure the web sites meet the publishing standards for health websites in Australia are dealt with by the project team when the content management system is being developed. In 2011 the external review of HFA had recommended that all Foundation websites meet the minimum standards and iron out inconsistencies. After some years of working individually through best practice guidelines, and for some local Foundations, having difficulty resourcing their websites adequately, it is a welcome step to be able to deal with all of these issues at once.

The project team will be led by Natasha Coco at HFA with representatives from all State/Territory Foundations.

This work has been made possible by a grant to HFA from the Australian Government Department of Health. #

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia

YOUTH UPDATE

Hannah Opeskin



FACTORED IN IMPROVEMENTS

Factored In is in the process of being further developed to reflect the needs of the young people who use it. A redesign and restructure is estimated to start in September and a review panel of young people has been established to ensure that the website continues to reflect the wishes and interests of young people with bleeding disorders.

We are planning on changing the entire site to make it look and feel new! This includes a new menu, news feed, new calendar and an even an updated Q & A section. The site will be so much easier and clearer to use!

If you want to help out with the website, have your say about design concepts or see the design before anyone else then join the review panel!

If you are interested please contact Hannah Opeskin hopeskin@haemophilia.org.au

GOLD COAST CONFERENCE

This year, the Australia and New Zealand Haemophilia and related Bleeding Disorders Conference will have many youth activities including a comprehensive and exciting youth session involving topics such as transition and disclosure as well as a Youth VIP event.

Meet new friends and say hi to your old ones at the Youth VIP Meet & Mingle social event.

Get some great advice and be involved in cutting edge discussions on sex, transition and disclosure.

If you haven't registered yet, head to the HFA website: www.haemophilia.org.au/conferences

The HFA conference is a great opportunity to make new friends, see your old ones, learn about exciting new treatments on the horizon and get involved in some controversial topics!

I can't wait to see you all there! 🎉

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



1 - 3 OCTOBER 2015 • GOLD COAST

YOUTH NEWS

YOUTH GETTING INVOLVED

Have you been to an Australia/New Zealand Conference before? Here are some experiences from other young people across Australia. It's not too late to register!

Dustin:

Attending conferences is a great way to meet others in a similar situation to yourself and make new friends. It's an excellent opportunity to learn from those who have been through it all before, and to help others by sharing your experiences. Plus it's always exciting to hear about what the future promises for bleeding disorder treatment and care. I would highly recommend attending an Australia/NZ Conference!

Emily:

I went to the World Hemophilia Congress last year and it was amazing. I really enjoyed meeting other people with similar issues as me and it made me feel less alone in dealing with things. It is definitely worth while going to the Conference if you can because there is always more to learn

Dressed for success: youth participating in a challenge at the WFH Congress



Young people from around the world at Congress in Melbourne



WHAT IS IT LIKE TO BE A MODERATOR FOR FACTORED IN AND WHY YOU SHOULD THINK ABOUT BECOMING ONE!



FACTORED IN
FACTOREDIN.ORG.AU

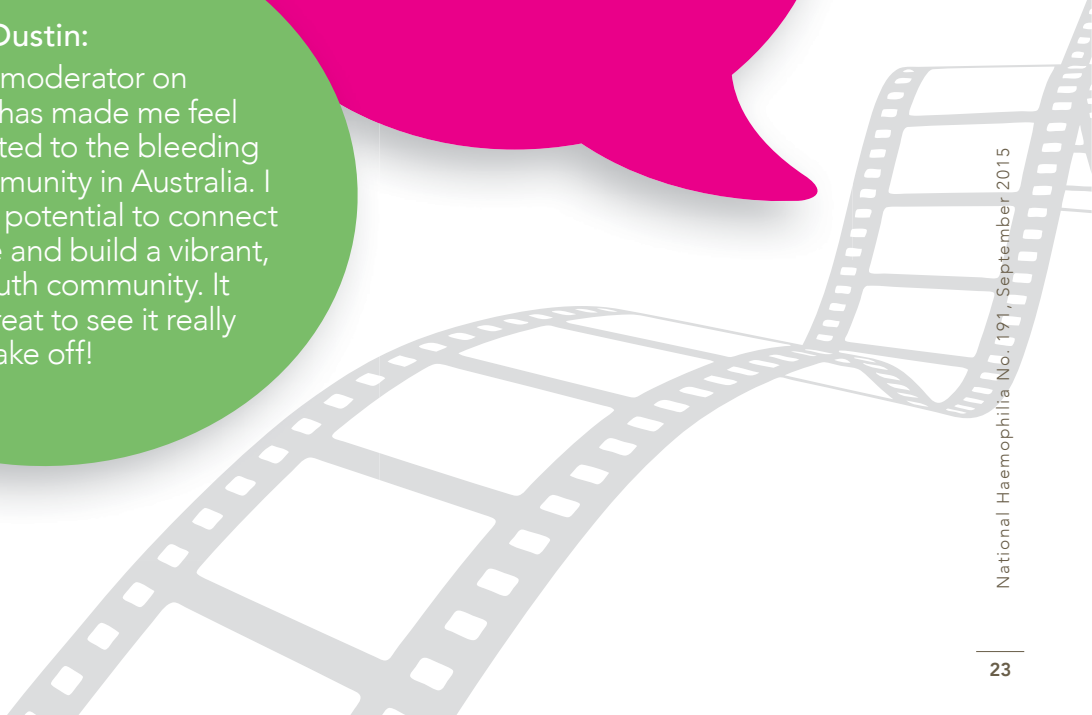
WHY JOIN?

AGED BETWEEN 13-30 HAVE A **BLEEDING DISORDER**, CARRY THE **GENE** OR ARE A **SIBLING** OF SOMEONE WHO DOES? **THEN WHY NOT?**

- GET SOME **SERIOUSLY GOOD** INFORMATION
- ASK QUESTIONS**, EVEN ONES YOU'VE BEEN TOO EMBARRASSED TO ASK
- TAKE PART IN **COMPETITIONS**
- COMMENT** ON OTHER PEOPLE'S STUFF

Dustin:
Being a moderator on Factored in has made me feel more connected to the bleeding disorders community in Australia. I think it has real potential to connect a lot of people and build a vibrant, national youth community. It would be great to see it really take off!

Emily:
Being a moderator for Factored In is great fun. Filming for Factored In was a fun experience and hopefully our work encourages people to use the website, so we have things to moderate!



CALENDAR

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/conferences

Haemophilia Awareness Week

11-17 October 2015

Tel 03 9885 7800

Fax 03 9885 1800

Email hfaust@haemophilia.org.au

www.haemophilia.org.au

World Haemophilia Day

17 April 2016

www.wfh.org/whd

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.

Baxalta

CSL Behring



Improving treatment and care through representation, advocacy, education and research

HFA MEMBER SURVEY UPDATE

A very big thank you to everyone who participated in the HFA National Community Survey. We received around 200 responses, and these are a very important part of helping us plan for the future.

With your comments about where you think HFA needs to direct its strategic work, education resources, research and communications, HFA will now collate and analyse the results. An interim report will be presented to the HFA

Council in October 2015 and a summary report will be published in National Haemophilia – so watch this space!

And big congratulations to those who entered the prize draw and won some amazing gift vouchers!

First prize (\$200 gift voucher) – Barker Family, VIC
Second prize (\$100 gift voucher) – M. Oversby, WA

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