

# THE MISSING FACTOR



**HOW TO ACCESS  
THE NEW HEP C  
TREATMENTS**

**ROADTRIP**  
*for all Victorians with  
Haemophilia & HIV*

**FIGHTING FOR THE  
RIGHTS OF WOMEN WITH  
BLEEDING DISORDERS**

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## DIARY DATES

Regional Visit to North East Victoria —  
Date to be confirmed

Haemophilia Awareness Week —  
9th - 16th October

Ladies Day — Sun Oct 23rd (TBC)

Dads Event!!! — Oct (TBC)

AGM & Christmas Picnic —  
Sun 27th Nov at Scienceworks

Youth Camp —  
Early December (TBC)

## A word from *our* Vice President, Sharron Inglis

### Committee of Management

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#### Vice President

Sharron Inglis

#### Treasurer

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#### General Committee

Kate Apted

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Karen Donaldson

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Dan Korn

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Erika Mudie

A warm hello to all as we move into Autumn and Winter. We have been very lucky with the warm sunny days, but I am sure that many are wishing for more rain. Leonie, our fearless and mighty president is away on a well-earned holiday. We all hope she is getting much rest and not thinking of us all back here in Australia.

We always seem to be busy here at HFV, whether we are staff, on committee or helping out on a sub-committee or casually. It is amazing to be part of such a wonderful community that cares deeply for one another. This includes our amazing and tireless staff, Andrea and Julia, who always go above and beyond.

One of our biggest annual events is the family camp, held near Neerim South again, at Forest Edge camp. It is such a tranquil site. The youth program ran again this year with much success. There are many little ones who are busting to get a blue youth leader T-shirt.

It's amazing what can happen at camps too. One minute we were talking about a trivia night as a fundraiser, and the next we had a group of mums that had formed a committee and had pen and paper out, and started organising a big event for next year! Some of these mums were new to camp and had only met the night before.

A big thanks to Janine Furmedge from RCH for travelling all the way to camp to supervise treatment time. It is always one of the most important and beneficial times at camp. We were thrilled that she stayed long enough to swing from

the high ropes too. Very brave!

One of the issues raised at camp was the issue of women's care. I have just attended the HFA Council Meeting in Melbourne and I am pleased to say that it is high on their agenda too. They are developing booklets on women and bleeding, but in the meantime are close to releasing fact sheets that we can take to our GPs etc so we can get the correct care. I am so excited about this development. Thanks to Suzanne at HFA.

Our Grandparents lunch and catch up was well attended this year. There were 17 people there from all around the state, mingling and sharing their stories. The lunch was delicious. We had a raffle and a small auction (hysterical actually) and raised over a hundred dollars. Thank you to Marie and Jackie for organising this event, which is in its 9th year.

Thanks also to Jackie & Neville Touzeau and Marie & Michael Ramage for all their hard work in organising the Bunnings BBQ fund raiser for HFV. So much work went on behind the scenes to enable this event to happen. Unfortunately it clashed with our family camp so many potential HFV volunteers were unable to assist. Thankfully Jackie and Neville spread the word throughout their local community groups and managed to staff the event for the whole day selling over 60kgs of sausages and raising well over \$1000 for HFV programs and raising awareness of haemophilia. Interestingly the father of a HFV member happened to drop into the Eltham Bunnings on the day, con-

Opinions expressed in the HFV Magazine do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres.

All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control.

nected with our volunteers and went on to attend the grandparents lunch!

Thanks again to all those who assisted in this event and to all of those who continue to raise funds for HFV through your own initiatives. Your work is sincerely appreciated and assists our community greatly.

The Men's Retreat continues to be a really important peer support event on our calendar, and was a great success again this year with a few new faces. One of the 'new' participants actually cancelled his plans to attend a formal function on Saturday evening to stay longer at the retreat! It was thoroughly enjoyed by all.

HFV is excited to announce the formation of a new Dad's Group. There will be more information about the first event in the next edition of the newsletter – so watch this space! Dads are an important part of our community, supporting us women and kids.

Please remember to use MyABDR to record your treatment. It is so important for our community to continue to have access to products and one of the ways we can ensure this is through recording data. It is set up so there can be no invasion of privacy. There is a lot of useful data that can be extracted from MyABDR and this may be used to look at bleed trends and statistics etc. So please get into the habit of making it a priority.

OK. That's enough from me. I could go on for hours about all that is being done and all that has been achieved and all that we intend to achieve. Please remember that if you are ever interested in being involved, however little time you have, what you get back is more than twofold. I love it. Take care.

Sharron Inglis

## #girlsmakeyourmove for the rest of your lives

The Turnbull Government is launching a landmark awareness campaign to encourage younger Australian women to 'make your move' after bombshell new research found teenage girls were only half as physically active as their male peers.

The #girlsmakeyourmove promotion will be headed by a series of fresh TV advertising spots starting from tonight, plus a social media campaign, featuring girls getting active and involved in physical activities or sports they enjoy.

Minister for Health Sussan Ley said the campaign comes on the back of new research showing nearly 60 per cent of girls aged 15-to-17 reported undertaking little-to-no exercise or physical activity compared to one-third of boys.

"This campaign was a fun way to encourage young women in their teenage years to build their bodies as they are growing.

"It aims to tackle this sliding door moment in a young woman's life when they actually are laying down the foundation for the rest of their lives.

"Physical activity in the teenage years lays down the muscle and bone you need for the rest of your life. It's a unique time as your body develops and the greatest opportunity to build up strength for your later years'.

"It will also help us to tackle a serious "epidemic" of diseases and chronic conditions facing this current generation if they did not exercise more.

"The research is telling us around the late primary to early high school age girls first engage in some form of physical activity within peer groups. And if that first experience is not enjoyable the idea of exercise and sport also can become a negative," Ms Ley said.

"Yet we know, for girls, exercise and physical activity is the number one way to prevent illnesses later in life, like osteoporosis, which affects almost one quarter of all Australian women aged over 50."

"And we're doing it by playing physical inactivity at its own game – through inactive pastimes like social media and TV."

The Hon Sussan Ley MP  
Minister for Health,  
Minister for Aged Care  
Minister for Sport

Media Release 28/2/16



## Me — the app that could end years of suffering for thousands of women

MONTREAL, March 8, 2016 – Sixteen years. That is the average time a woman can suffer before receiving a proper diagnosis of a bleeding disorder and, moreover, receiving the proper treatment that will change her life forever. With the new app Me, the Canadian Hemophilia Society (CHS) provides women concerned with their frequent and heavy menstrual bleeding with a practical and reliable tool to help them evaluate their menstrual flow and present their doctor with quantified evidence. This very simple assessment may allow them to finally put a name on what has been upsetting their lives for so many years.

### Me – Period Flow Assessment

The CHS created, in collaboration with Mirego, a mobile application called Me – Period Flow Assessment. It is a very easy and free app found on iOS and Android platforms. Me features the same components as a conventional menstrual chart which allows the assessment of blood saturation level of pads and tampons, augmented with the benefit of automatically calculating menstrual scores. Women are warned when their score represents a risk of possible menorrhagia and are recommended to contact their doctor for further assessment. It is important to understand that this is not a menstrual calendar; the CHS developed this app specifically for women who have bleeding issues. For discretion, only Me is displayed on mobile devices.

### Background

For more than fifteen years, the CHS has played a world-leading role in raising awareness about bleeding disorders that affect women. With this expertise, in 2012, the CHS initiated a national awareness program: CODerouge | WHEN WOMEN BLEED TOO MUCH.

As part of this program, the CHS attends various medical conferences, such as the Annual Clinical and Scientific Conference of the Society of Gynaecologists and Obstetricians of Canada (SOGC) or the Annual Family Medicine Forum, in order to increase knowledge among health care providers about the diagnosis and management of inherited bleeding disorders. Although participants at these conferences have been very interested in a conventional menstrual assessment chart distributed by the CHS, also available on its website, it became quite clear that a mobile app would be the next step.

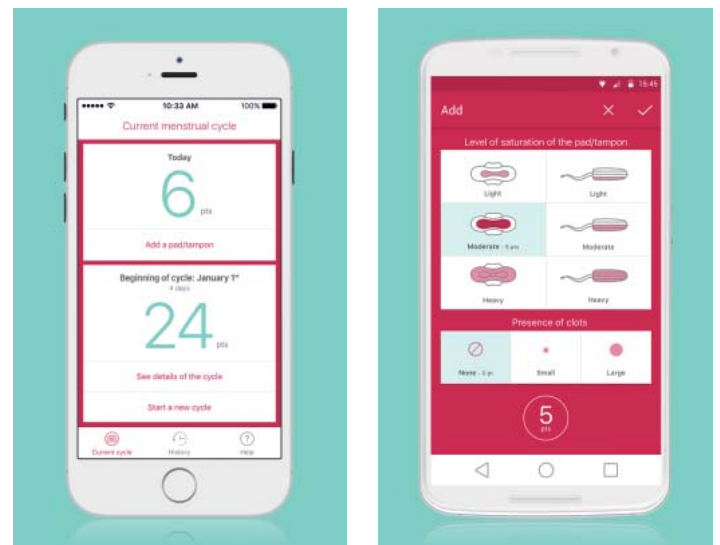
With Me, the CHS hopes to substantially increase the number of women who will receive a proper diagnosis. At this time, 90% of women affected with a bleeding

disorder do not know about it! Me can end up being the beginning of the answers they have sought for so long. With Me, school weeks spent in bed, missed business meetings, activities cut short, could become things of the past. Me, a remarkable tool that will allow so many women to take control over their monthly struggles, to take control of their lives.

Links to download the app:

iOS: <https://goo.gl/SuXlF5>

Android: <https://goo.gl/1KOpJU>



### About CODerouge

CODerouge | WHEN WOMEN BLEED TOO MUCH has been created by the Canadian Hemophilia Society to help identify undiagnosed women with bleeding disorders, such as von Willebrand disease, and to ensure that they have access to appropriate medical care. To learn more about the symptoms related to bleeding disorders and on the CODerouge program, please go to [www.coderougewomen.ca](http://www.coderougewomen.ca).

## HFV Family Camp 2016

Without a doubt the 2016 HFV Family Camp was a resounding success. Both Andrea and I find this to be a truly beautiful location. Set amongst rolling hills with bright green fields, Forrest Edge is just picture perfect and a wonderful place to unwind with the help of our HFV families, our Youth Leaders and the Purple Soup Team.

So Friday night kicked off with a BBQ kindly cooked by a number of HFV members (thank you!). We were then treated to an information session run by the Neerim District Historical Society. This included an insight into the old regional timber industry, how the timber rail road bridges were built and a demonstration of the tools used for timber from back in the day. We also got to hear from a steam train driver who had the job of driving the old steam trains over the timber bridges (it sounded terrifying!). It was a fascinating insight into the local history of the area and made us all quite glad we could rely on Bunnings for our timber needs.



It was then well and truly dark and we were ready for our camp fire. This was a special moment as we were down by the river under a blanket of stars, sharing challenges we have faced and understanding about how important it is to be positive, kind to ourselves and kind to each other – all whilst enjoying marshmallows!



Saturday morning saw the arrival of Janine Firmedge and the 'treatment session'. This has always been a particularly

important session for camp. It is where a couple of brave souls, usually our youth leaders, agree to administer their treatment as a demonstration. It shows our young children that self-infusions can be done, it shows them that sometimes you may not get it right first time around, it shows them that they are not the only ones who have this as part of their day to day lives.



As an organisation we realised at this camp that we need to assign more importance to this 'treatment time' and not to feel pressure to rush off to activities. It is an important activity in itself - in fact it may well have the most positive impact of all our activities. To see families stand around watching, learning, practising on the equipment provided by Janine or even to feel comfortable enough to attempt their first self-infusion, is absolutely priceless. And to see the young kids realising for the first time that all these big kids are the same as them, they have to do treatment too, they help the siblings with their treatment and there are other boys with ports! It really is a uniting moment for our community and something we will not rush but celebrate at future camps.



Now it was time for our group activities. The adults had an opportunity to focus on mindfulness whilst the kids were either off, braving the cold water doing river sledding or tackling archery.



Then it was time for the high ropes. Wow, this was so challenging for a number of people but in true HFV fashion I got to witness huge feats of inner strength for a number of our mums who overcame their fears, accepted the support of their peers and took those steps onto the ladder, poles or across the wires. Such a great experience to watch and see this supportive group we are part of.



Following lunch the ladies headed off for their 'Secret Women's Business'. I could tell you all about it but it's a secret so I can't, except to say it was held at the most beautiful home-  
stead gardens with amazing nibbles and drinks provided by members and businesses of the local community in Neerim South, so a big thank you to all of those who offered their time, home and produce to HFV.



Then the men folk took the opportunity to head off for some Secret Men's Business of their own, enjoying a fabulous spread of food, not sure what happened being secret mens business but I know a few fishing lines were thrown in the river.

The evening turned out to be such a great night with the Purple Soup team running a trivia session. It was mixed teams of kids and adults, and many members embraced the gold theme. I think it is fair to say no-one managed to get through the night without slightly embarrassing themselves with the team events, including a Michael Jackson dance off, Marilyn Monroe impersonations or singing and dancing

with animal shower caps on our heads. It was all great fun and a really nice opportunity for the parents and children to spend some quality time together.



The weather was very kind to us on Sunday and we ended up enjoying a few rays of sun during our activities. After lunch we got to spend some time watching the slide show produced by Isabelle Inglis of the weekend. There were some absolutely priceless memories.

The Purple Soup team also awarded the Michael Lucken Camp Spirit Award to two very deserving recipients — Caitlyn Williamson and Scarlet Lucken. Both of these recipients showed true Camp Spirit throughout the weekend.



Our thanks go to the camp sub-committee and Andrea who all spent many hours preparing for this camp to ensure another wonderful experience for our families. Thank you to the Field family who were instrumental in organising the Men's and Women's Secret business, engaging with the Historical Society and various members of the Neerim South community who then supported our camp in various ways. Also a big thank you to the Purple Soup team — Tim, Bec, Nigel and Taylor who again worked in partnership with HFV to provide a comprehensive program with plenty of 'warm and fuzzy' moments that make our camps such memorable experiences. Finally, a big thank you to our Youth Leaders who provide so much support to the younger kids, are passionate, inspirational and wonderful role models for the next generation.



## Haemophilia, travel & *scratching that itch...*

I have an irrepressible itch to travel and see new places. It's an ironic situation, because growing up with severe haemophilia made scratching that itch more challenging than it would be for most people. But I doubt that I'd be this way in the first place if I had been born with a normal clotting system. My family, doctors, and other role models all did what they could to raise me to manage my care on my own, and I took that idea of independence and ran with it.

In fact I probably took it a lot further than they had any idea I might go. When I graduated from university, my first job was literally on the other side of the planet: Singapore is 176 degrees of longitude west from my home state of South Carolina in the US. Even at jet speed, flight itineraries from one to the other are 28 hours long.

Of course, to benefit from travelling, haemophiliacs don't have to close their eyes, drill a hole through a globe, and set off for wherever the bit emerges on the other side. You can learn a lot about the rest of the world - and a lot about yourself too - by spending time in any of Australia's near neighbours. Some of my favourite travel memories are from weekends in Indonesia and the Philippines, and I'm eager to go back again.

That's not to say that haemophilia can just be ignored as you make your travel plans. Having even mild haemophilia is good cause for taking several doses of clotting factor with you to a foreign country. In fact it's simpler to do that than to try to arrange ahead of time for access to clotting factor at a hospital at your destination. And unless you're planning a vacation to Norway or Antarctica, when you carry your own supply with you as you go, every step of the trip deserves extra planning because keeping your medicine cool will be a much bigger obstacle than any airline delay.

Imagine getting almost all the way to your temperature-controlled hotel room but having to sit through an hour-long traffic jam from the airport. Did you forget to pack your medicine in an insulated bag? Or



maybe some perplexed airport security staff forbid you to carry on your frozen gel-packs because they couldn't quite figure out how the security screening rules applied to them. If so, you're now relying on your taxi having air conditioning that can keep up with the tropical sun and scorching pavement - if it's working at all.

To successfully face situations like that, I recommend that any haemophiliac planning to travel start small and





work your way up to bigger trips. Go follow your favourite footy club interstate on a cool winter weekend, and take some clotting factor with you even if you know you can rely on an HTC at your destination. Get accustomed to the challenges that keeping it safe and near to hand might create.

For example, it would be wise to get in the habit of showing up an hour early at the airport in case the security screeners have extra questions about your medicine and its ancillary supplies. (For the most part, I breeze through airport security with barely any extra checks, but it helps to have several copies of your prescriptions, a note from your doctor on HTC letterhead, and to notify the screeners what to expect before they put the bag through the imaging machines.)

Once you've got a few weekend hops under your belt, think about taking a one-week trip somewhere you've never been. It can teach you something you'd never expect, and inspire you to fill up your passport with so many stamps and visas you'll need the embassy to put in extra pages. My most profound travel experience of all was visiting a showcase village in rural Laos while I was working in nearby Cambodia.

There, after being shown the new school that generous foreign donors had just built, I asked the family I was sitting with if there was anything I could do for them. The mother shyly asked if I could spare paracetamol, plasters, or antibiotic ointment for her children. The small cluster of houses where they lived was much too isolated for them to easily buy even the most basic medical supplies, so any common fever or careless burn could quickly develop into a major health crisis.

As I emptied out my first aid kit for her, it shocked me to realize that these items I'd never think twice about could mean so much for her children's well-being. The walking boot I wore to support my ankle against a recent injury probably cost more than five dozen of those first aid kits put together, to say nothing of the hundreds of dollars I had spent on my smartphone or the scratch-proof lenses in my sunnies.



I sat there and realized how profoundly fortunate I was to benefit from the complete accident of birth that put me in a comfortable home just a few kilometres from the state HTC, rather than that tiny cluster of houses so distant from even the nearest chemist. It's a lesson I haven't forgotten to this very day.



*Dan Korn is a technology geek from the US who, despite recently joining the HFV Committee of Management, still has a hard time spelling haemophilia with two a's. E-mail any questions you have about haemophilia, travel, or both to [dan.korn@gmail.com](mailto:dan.korn@gmail.com)*

# *Perth woman fights for rights of females living with bleeding disorders*

By Briana Shepherd Updated  
Sun 17 Apr 2016

**Chloe Christos was 14 years old when she got her first period.**

She did not stop bleeding for five years.

"I knew it wasn't quite right, but I was also embarrassed to talk about it. I felt very different and pretty alone," Ms Christos said.

Ms Christos developed severe anaemia and barely made it through high school. At 19, she was given weekly iron infusions, but after seven months her iron level still sat terrifyingly low.

"I was tested and it came back that I had von Willebrand disease," she said.

Von Willebrand disease (VWD) is a lifelong bleeding disorder that prevents blood from clotting properly.

While haemophilia is perhaps the most recognised of bleeding disorders, and it can be the most severe, it is not the most common — VWD is.

For Ms Christos, the diagnosis was not a cure, and she went through many more years of pain, severe bleeding and frustration.

"I came across a lot of people, even in the medical profession, who didn't realise what it meant for women to suffer from a bleeding disorder," she said.

Ms Christos also presents low levels of factor VIII, a common feature in VWD patients, and the factor associated with classic haemophilia.

A stylist and art director who has worked around the globe, she was put on a synthetic drug for seven years, which helped release factor levels in her body but also resulted in what she called "terrible" side effects.

"I love and am very passionate about my work so I just kept going," she said. "But I think I have ended up in the emergency room at almost every country I've travelled to."

## **Finding the right treatment**

Ms Christos settled in Perth around three years ago and started receiving treatment at the WA Centre for Haemophilia and Bleeding Disorders.

She declined suggestions that she undergo a hysterectomy. "I don't know if I ever want kids but I never wanted to get rid of what made me a woman. And I was terrified of being in my mid-twenties and going through menopause," she said.

Ms Christos was also eventually taken off the synthetic drug.

"It was terrible. I was suddenly right back to where I felt I couldn't work, I couldn't leave the house," she said.

"I definitely became frustrated ... I would end up in the emergency room, sometimes three times a week."

Looking for answers, Ms Christos reached out to the next closest haemophilia centre, and a week later she travelled to Adelaide to seek a new treatment plan.

Ms Christos said that meeting changed her life. She soon started taking a blood product which is used for haemophiliacs across the country, mostly men.

"I remember the first day I used the blood product," she said.

"I was surrounded by friends who have supported me so much through this journey at the treatment centre in Perth. I had not felt that good in years."

Ms Christos is now 27 years old, and for the first time in 13 years she has a normal four to five day period.

"That happened for the first time less than a month ago. I truly feel so lucky that I have found something that works for me," she said.

A consultant haematologist at the WA Centre for Haemophilia and Bleeding Disorders, Dominic Pepperell, said he hoped that women did not feel it was more difficult for them to receive treatment.

"I think that women with bleeding disorders are at a



disadvantage because they're more likely to be affected day to day just by the mere fact that they have menstrual bleeding," he said.

"It can really affect people's lives from that point of view.

"I hope that people don't find that [treatment is] more difficult to access, or less useful."

### **Call for more awareness of bleeding disorders**

While Ms Christos' journey has not been easy, she knows it could have been much worse.

World Federation of Hemophilia chief executive Alain Baumann said 75 per cent of people with bleeding disorders still received very inadequate treatment, or no treatment at all.

"The percentage is even higher for those with VWD and rare factor deficiencies," he said.

"In many developing countries, the lack of access to care and treatment often leads to misdiagnosis."

Mr Baumann said there were still misconceptions about bleeding disorders.

"Generally speaking, for many years people believed that only men could have symptoms of haemophilia and women who have or 'carry' the haemophilia gene do not experience symptoms themselves," he said.

"We are now more knowledgeable that female carriers of the haemophilia gene do experience symptoms.

"Unfortunately many women will live with these symptoms for years without being identified and diagnosed, and this occurs in both developed and developing countries."

### **'We can still do more'**

Ms Christos is now a strong advocate for females with bleeding disorders around the world.

In July she hopes to raise enough money to travel to the World Hemophilia Congress in Orlando, where she plans to volunteer at the very first women's booth.

"It's a sign that things are changing. But we can still do more," she said.

She is working with other women on a proposal for a government funded data collecting project.

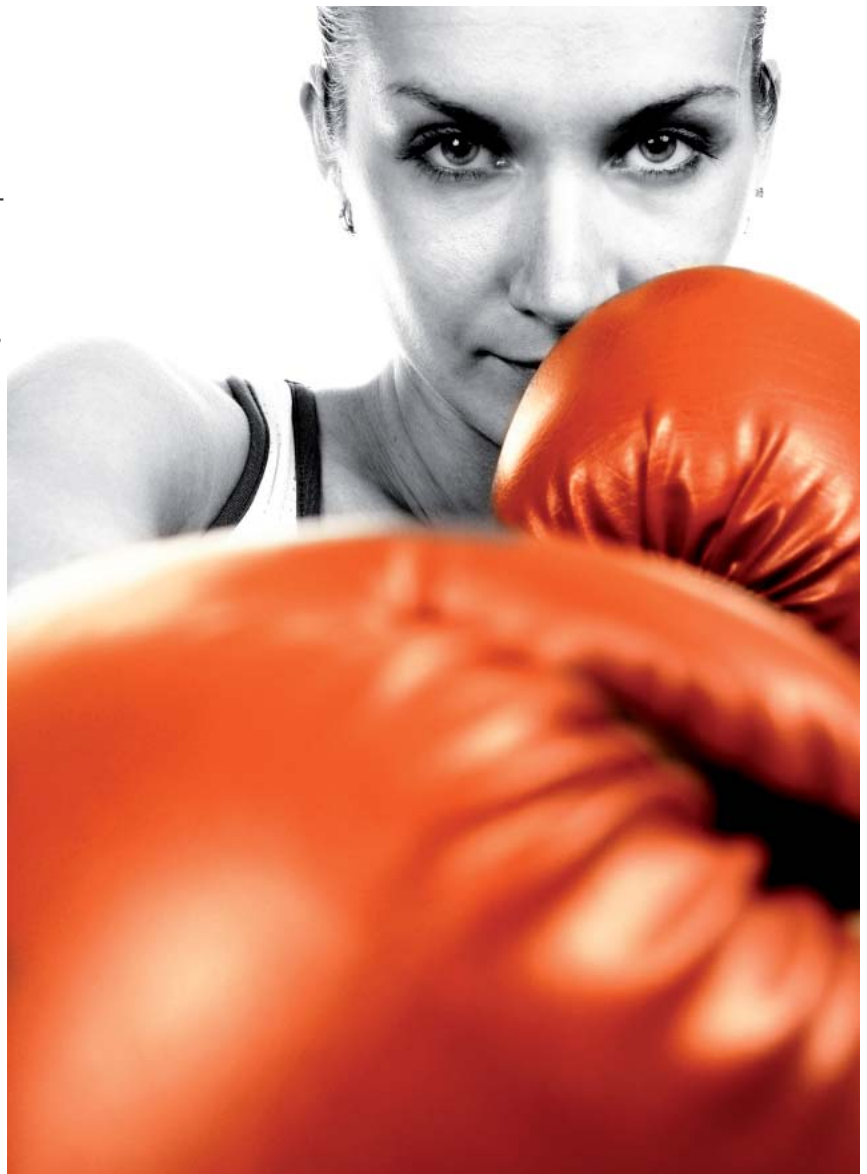
"A lot of statistics and data is kept on diagnosis and treatment for men. There's almost nothing on women that doctors can refer to, and I hope we can change that," she said.

It has been a long road but Ms Christos said she hoped by sharing her journey, it could help other women receive the correct diagnosis and treatment they deserved.

"It has always felt like this taboo subject," she said.

"I am speaking out about this because I want women around the world to receive adequate care and treatment for bleeding disorders."

**Reprinted with permission from the ABC.**



# New Hepatitis Treatments

## Access to new hep C drugs

*Update from HFA*

From 1 March 2016 new breakthrough hepatitis C treatments will be available on the PBS:

- sofosbuvir with ledipasvir (Harvoni®)
- sofosbuvir (Sovaldi®)
- daclatasvir (Daklinza®)
- ribavirin (Ibavyr®).

"This is fantastic news for people with bleeding disorders and hepatitis C," said Gavin Finkelstein, President of Haemophilia Foundation Australia. "They have been waiting so long for access to treatment to cure their hepatitis C. Many have seen their liver disease progressing and were despairing. This decision by the Government will change people's lives and we would like to congratulate Minister Ley for seeing the process through to make these treatments available and affordable to all Australians with hepatitis C."

The new treatments have high success rates – usually more than 90% across the entire hep C population:

- Genotypes 1-3 – oral treatment with tablets; no interferon injections
- Genotypes 4 and 6 – sofosbuvir + peg interferon/ribavirin
- Shorter treatment courses – usually 12-24 weeks
- Fewer and usually only minor side-effects
- People with cirrhosis still have relatively high cure rates but need specialist and individualised care and monitoring.

## WHAT IF YOU HAVE A BLEEDING DISORDER?

HFA has had initial discussions with the Australian Haemophilia Centre Directors' Organisation (AHCDO) and hepatitis and HIV/HCV co-infection specialists:

You would need to have a recent liver health assessment before you could be considered for treatment. Don't wait; if you haven't already, make your appointment now!

- **Don't know where to start?** Ask your Haemophilia Centre for a referral
- **Do you have hepatitis C?** Make an appointment with your hepatitis or liver clinic to discuss your treatment options
- **Do you have HCV/HIV co-infection?** Talk to your HIV or infectious diseases specialist about the new treatments. There may be some HIV drug interactions to take into account as well as other factors, and they will work out the best treatment regime for you
- **Do you have more advanced liver disease/cirrhosis?** Talk to your hepatitis or HIV specialist about liaising with your Haemophilia Centre in case of complications
- **Not ready for treatment?** Make sure you still have your liver health checked regularly and stay in touch with your hepatitis clinic about what's new
- **And for comprehensive care, talk to your Haemophilia Centre** first and let your Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

For more information, read the PBS factsheet on the new hep C treatments -

<http://tinyurl.com/pbs-hepc>

Updates are also available on the Hepatitis Australia website – [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com)



## MEN'S RETREAT 2016



Our men's weekend retreat was again held at Lochinver Homestead in central Victoria in early March. We had a total of 11 men, youngish and oldish, mild's and severe's, A's and B's.

The Homestead comfortable slept us all and the air-conditioning was much appreciated in the 40 degree conditions.

Alison and Sharon were again our hosts, and we couldn't be more pleased with how well they look after our every need.

Sharon cooked for us, guided our meditations and massaged us all.

Again this format has proven the importance of men getting together as a group and just talking. It constantly amazes me how without an agenda we fell into a comfort zone where we could share stories, knowing that we all understood each other and felt no embarrassment in doing so.

We all left on Sunday, all looking forward to next year's weekend.

The weekend has been pencilled in for late February 2017, so express your interest early — we'd love to see some more new faces.

Zev Fishman

Comments from participants:

*I must thank you guys. It was a privilege to spend the weekend with you and I thank you all for being so welcoming and inclusive.*

*The great benefit was meeting and talking with other haemophiliacs about shared experiences.*

*This retreat helps me feel less isolated which helps maintain a positive state of mind*

Comments from the venue hosts

*It was an amazing weekend with the most amazing gentlemen. I am so looking forward to seeing all their faces and smiles again next year. I feel so privileged to be in their presences. To have earned their trust in such a short time is humbling. This retreat has also for me been a life changing experience.*

Hello. I'm Matt Powell, Peer Support worker at Straight Arrows. I'm organising the Road Trip and Retreat for all people in Victoria living with both haemophilia and HIV.

Letters of invitation have been sent out to all of relevant people and I have received enough interest to make this thing a goer. I'm writing now to send the word out that the deadline for expressions of interest is June 16th. It's not a super-strict deadline, but we need to have a good idea of numbers so we can budget and plan properly. Even if someone does not want to go, a reply would be greatly appreciated.

The idea with this retreat is that participants get in contact to help plan the retreat – when, where and what we do etc. I, Matt Powell, will coordinate everything with assistance from my colleagues at Straight Arrows. There are guys living all over Victoria, so we need to plan a route to go and pick everyone up and travel on to our retreat destination.

Nothing yet is set in stone because I want as much feedback and interaction as possible. But the clock is ticking and I need a good idea of numbers by June 16th. There is no cost to anyone who attends.

I have already set up a secret Facebook group that is going to be our main form of communication – it is very secure and the only people who will ever see the posts are people that I have invited into the group.

If anyone reading this knows of a person living with haemophilia and HIV - please let them know about this unique project. I know many guys are curious about how others have fared with the double challenge of living with both haemophilia and HIV. I am also very aware that guys may not want to relive the traumas of the past. I get it, I've lived through it myself. But I am convinced of the great benefits that come when peers have the opportunity to share their experiences.

So with that in mind, if you are reading this and know of anyone (family or friend) who is living with both HIV and haemophilia, please encourage them to contact me - details below.

And if you are reading this and you have haemophilia and HIV, then I reckon you should get on board – we are all different but we share something that no-one else can truly understand. Even if you don't want to go, maybe you'd at least consider joining the secret facebook page I've set up to establish some type of contact. Come on, I know you're curious.

Anyhoo, thanks for reading – wish us luck and onward we roll.....

Matt Powell  
Peer Support Worker at Straight Arrow  
Call – 0425 725 197  
Email – [peersupport@straightarrows.org.au](mailto:peersupport@straightarrows.org.au)





## ELTHAM BUNNINGS SAUSAGE SIZZLE

### What a day and what team!

Our committee and staff are so grateful to Jackie and Neville Touzeau who contacted the Eltham Bunnings and took on the role of organising a Bunnings BBQ to help raise funds for HFV. As we discovered there are quite a few requirements to follow with the correct permits and procedures to follow.

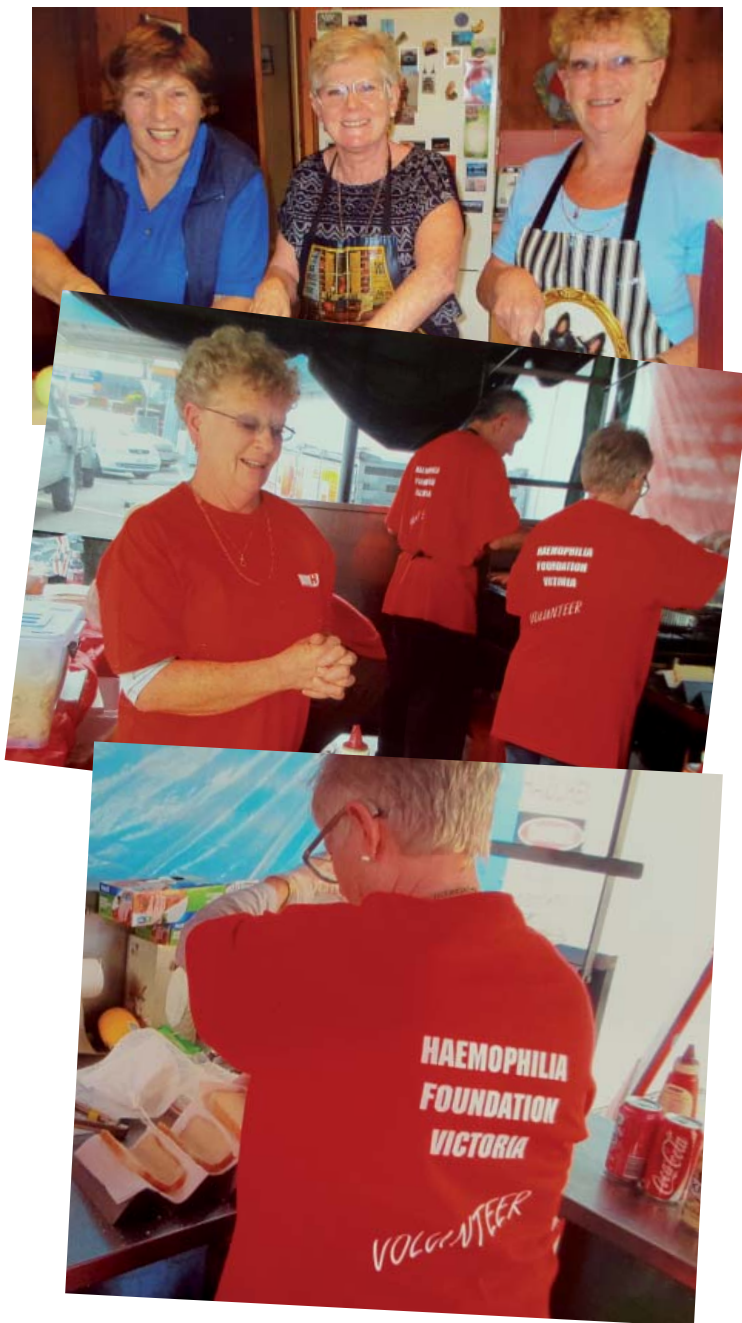
Normally we would have lots of volunteers to help assist but the BBQ happened to fall on the same weekend as our Family Camp so our usual rabble of helpful volunteers were busy on the high ropes and secret men's or women's business, but luckily there were a number of their friends that stepped up to help out, including HFV members Marie and Michael Ramage.

The day turned out to be amazing with the sun shining which encouraged the crowd. Over 60 kgs of sausages were cooked, bags and bags of onions hand chopped by the team and a steam of volunteers to help out from 8am until 4pm.

The event raised well over \$1000 which is a wonderful achievement and will help support our member programs.

#### A big thanks to:

Jackie & Neville Touzeau  
Marie & Michael Ramage  
Helen Sheldon  
Mary Dougan  
Ralph & Angela De Leo  
Bambi McLean  
Irene & Andrew Olynky  
Gwen Lakin



### FREE WEBCAST ASK THE EXPERTS PROSTATE CANCER: DIET, SUPPLEMENTS & LIFESTYLE

JOIN PCFA ONLINE ON WEDNESDAY 15 JUNE 2016  
#ASKTHEEXPERTS #MENSHEALTHWEEK

Join Prostate Cancer Foundation of Australia online  
during Men's Health Week  
Wednesday 15 June 2016 | 7:00 PM - 8:00 PM AEST  
Register here: [www.webcasts.com.au/pcfa020316/](http://www.webcasts.com.au/pcfa020316/)

# Mindfulness in Everyday Life

*If you let cloudy water settle, it will become clear. If you let your upset mind settle, your course will also become clear. From Buddha's Little Instruction Book (Kornfield: Bantum Books, 1994)*

**Mindfulness** is a form of self-awareness training adapted from Buddhist mindfulness meditation. It has been adapted for use in treatment of depression, especially preventing relapse and for assisting with mood regulation.

It has been described as a state of being in the present, accepting things for what they are, i.e. non-judgementally. It was originally developed to assist with mood regulation and relapse prevention in depression and has been found to have considerable health benefits.

These exercises are designed to introduce the principles.

## SOME MINDFULNESS TECHNIQUES TO PRACTISE

### One Minute Exercise:

- Sit in front of a clock or watch that you can use to time the passing of one minute. Your task is to focus your entire attention on your breathing, and nothing else, for the minute. Have a go - do it now.

### Mindful Eating:

- This involves sitting down at a table and eating a meal without engaging in any other activities - no newspaper, book, TV, radio, music, or talking.
- Now eat your meal paying full attention to which piece of food you select to eat, how it looks, how it smells, how you cut the food, the muscles you use to raise it to your mouth, the texture and taste of the food as you chew it slowly.
- You may be amazed at how different food tastes when eaten in this way and how filling a meal can be. It is also very good for the digestion.

### Mindful Walking:

- Here the same principle, while walking you concentrate on the feel of the ground under your feet, your breathing while walking. Just observe what is around you as you walk, staying IN THE PRESENT. Let your other thoughts go, just look at the sky, the view, the other walkers; feel the wind, the temperature on your skin; enjoy the moment.

### De-stressing Exercise:

- Bring yourself into the present by deliberately adopting an erect and dignified posture.
- Then ask yourself: "What is going on with me at the moment?"

- You simply allow yourself to observe whatever happens. Label any thoughts that you have and then leave them alone...just be prepared to let them float away. Attend to your breathing or simply take in your surroundings instead.
- Besides thoughts, there may be sounds you hear, bodily sensations that you are aware of. If you find yourself constantly elaborating on thoughts, rather than labelling them and returning to the neutral, remember to observe your breathing.
- When emotions or memories of painful events occur, don't allow yourself to become caught up by them. Give them short labels such as "that's a sad feeling", "that's an angry feeling" and then just allow them to drift or float away. These memories and feelings will gradually decrease in intensity and frequency.
- More importantly, you will begin to identify yourself as an objective observer or witness rather than a person who is disturbed by these thoughts and feelings. This requires practise but can then be used when ever you are stressed.

### Associated Breathing Exercise:

- Stay with any distressing thoughts for a few moments, then as you let them float away, you gently redirect your full attention to your breathing.
- Pay attention to each breath in and out as they follow rhythmically one after the other. This will ground you in the present and help you to move into a state of awareness and stillness.

1 Adapted from those in Elliston, P. Mindfulness in medicine and everyday life. British Medical Journal, Career Focus, 17th November 2001.



**Black Dog  
Institute**

*The Black Dog Institute is a not-for-profit organisation and world leader in the diagnosis, treatment and prevention of mood disorders such as depression and bipolar disorder.*





## PROBE Study

*Update from HFA*

How can haemophilia foundations have access to good quality data about the treatment and health experiences of people with bleeding disorders? The multi-national PROBE (Patient Reported Outcomes Burdens and Experiences) Study aims to do precisely that. Haemophilia Foundation Australia has joined the PROBE investigation team to be part of this important international study on the impact of living with a bleeding disorder.

PROBE is a patient-focused research project led by a global team of patient and academic investigators, including Mark Skinner, former WFH President, and Assoc Prof Alfonso Iorio from McMaster University, Canada, who have worked closely with HFA on the Australian arm of the study. The research will support efforts to improve treatment and comprehensive care programs in Australia and other countries around the world.

### Phase 1

Some of you have been involved in distributing and completing the surveys for Phase 1 of the PROBE study. Thank you for your support! We needed 35-50 completed surveys by the end of 2015 to have enough data to be analysed, and by Christmas had received 39 surveys, which was an amazing effort in a very short few weeks!

What did Phase 1 involve?

- Seeking ethics approval via Monash University, Melbourne
- Testing how clear the questions are
- Testing the methodology and the statistics that could be gained from the results.

Phase 1 tested a print survey on haemophilia only. Some Australian community members with haemophilia and carers or parents of children with haemophilia completed the draft questionnaire and gave feedback on the questions and instructions. The completed surveys and question feedback sheets were then scanned and transferred electronically to the PROBE research team at McMaster University for analysis.

### Results

HFA received a report on the Australian results in January 2016 and was invited to participate in an international meeting where the world-wide results were discussed:

- More than 700 surveys completed internationally
- Results demonstrated validity and that the research methodology was robust
- Phase 1 data is useful for understanding how to use the potential results but should not be used for advocacy at this point – wait for phase 3
- Australian feedback on questions was put in a spreadsheet and each comment addressed by the research team leaders
- As a result of global feedback, new questions will be added in Phase 2 for women who carry the gene
- For good comparable data, in future Australia needs to recruit more people with moderate haemophilia to complete the survey.

### Phase 2

The next phase involves reproducibility – testing an online version of the survey as well, and retesting the same community (ie, Australia) to see whether the results are consistent. Stay tuned!

If you have any questions about the PROBE survey, please contact Suzanne at HFA on 1800 807 173 or

[socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au); or visit <http://tinyurl.com/PROBE-Aus>.



## MEDIA RELEASE

Friday, 4 March 2016

# My Health Record roll-out a step forward for Australia, says the Consumers Health Forum

The new measures to accelerate roll-out of the My Health Record, the national electronic health records system, is an important step forward for Australia's health, the Consumers Health Forum said today.

The Chief Executive Officer of the Consumers Health Forum, Leanne Wells, said that the trials in the Blue Mountains and North Queensland of the "opt out" approach to My Health Record, were a vital test of the eHealth system. The current policy has been to leave it up to individuals to sign on for the electronic patient record and that has resulted in a slow take-up.

"The virtue of the "opt out" approach in which people would be automatically enrolled unless they specifically decline, will be a faster development of a digital health record for Australians, delivering greater benefits to patients and doctors sooner," Ms Wells said.

"We welcome the Government's renewed push on My Health Record. Consumers have been waiting a long time for the advantages of easily accessible electronic information about their health care".

"We are well into the digital age in the way we go about other every day activities such as banking, telecommunications and online shopping. It is timely that we reap the benefits of the role that digital innovation can add to our health and care".

"People want all their records about their health conditions, treatment, scans and tests in one place because they know it will improve health outcomes.

"My Health Record – once it is operating well and all health professionals and providers are using it to routinely log patient information and refer to that record should lead to better coordination, a decrease in duplication of tests and fewer adverse medical events.

"These are all the things consumers find frustrating, quite

apart from and negative impacts on care. So they need to seize the opportunity that My Health Record offers.

"We need all GPs and other health professionals to get behind My Health Record, for the benefit of patients and their own work efficiency and effectiveness.

"Patients and clinicians alike often complain about the breakdown in communication across health care teams and about the frustrations and time wasted in gathering the same information on repeat occasions. My Health Record is a key building block for a more effective, connected health system and a powerful vehicle for ensuring better linkage and coordination of care in the consumer's interest" said Ms Wells.

"My Health Record safeguards are designed to ensure patient records are secure and privacy-protected. Importantly consumers will be able to control who among designated health professionals are able to view their record."

"The Consumers Health Forum has long called for the move to an opt out scheme because we believe the sooner all patients and practitioners are part of eHealth, the sooner we can benefit from a truly 21st Century health system," Ms Wells said.

Media inquiries: Mark Metherell 0429111986

Mark Metherell | Communications Director

Consumers Health Forum of Australia



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WWW.FACTOREDIN.ORG.AU

**WIN AN  
iTUNES VOUCHER  
WORTH \$100!!!**

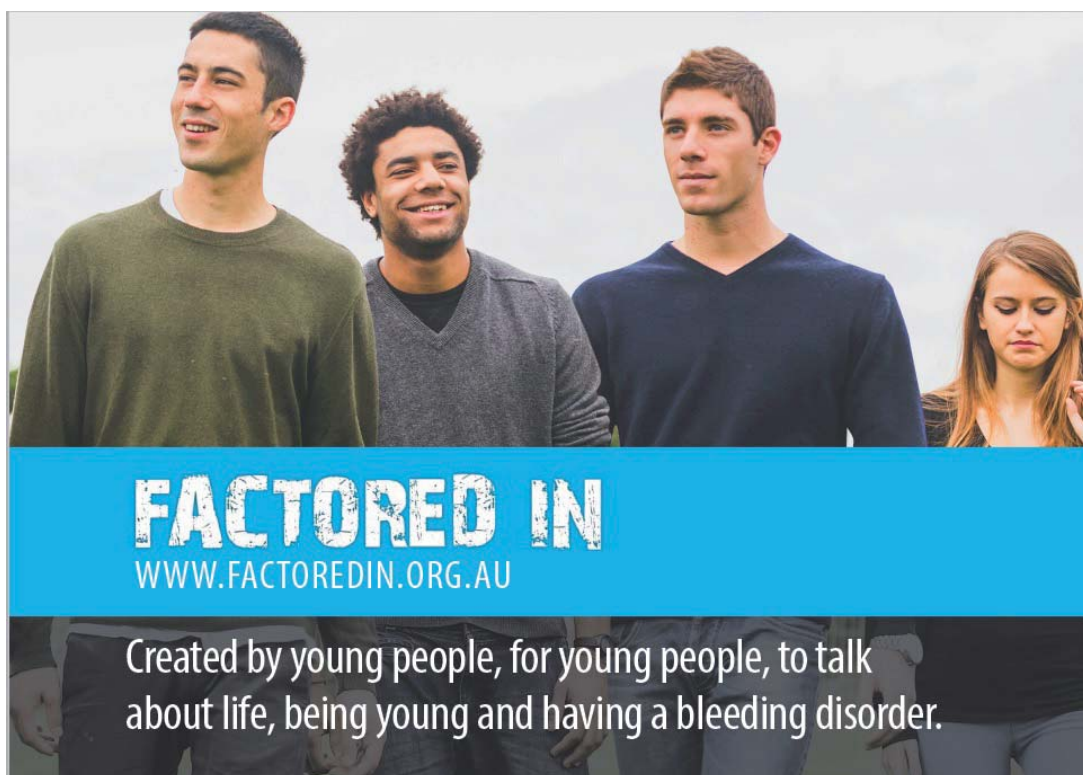
HFA has been redeveloping Factored In and was launched on May 24 2016!

Factored In is a youth oriented and driven website with robust and professionally reviewed information and has personal stories from youth living with a bleeding disorder or carrying the gene.

Celebrate the re-launch of Factored In by going into the draw to **win an iTunes voucher worth \$100!**

- Vote in the poll on the competitions page, “Welcome to the NEW Factored In”, Complete the entry form!!!

The competition is open until 7th June 2016 and available only to Factored In members aged 13-30 years have a bleeding disorder, carry the gene or are a sibling. If you’re not a member yet, make sure you sign up!



#### **What is Factored In?**

- Factored In is created by young people, for young people, to talk about life, being young and having a bleeding disorder.
- Get some seriously good information.
- Ask questions, even ones you’ve been too embarrassed to ask
- Take part in competitions and polls

#### **Who is Factored In for?**

- If you’re aged 13-30, have a bleeding disorder, carry the gene or are a sibling, Factored In is for you!

#### **What’s new with Factored In?**

- Factored In is now easier to use! Ask a question, read stories easily, participate in polls, read and navigate the site with ease!

Don’t forget to become a member so you can comment on other people’s stories and share your own!

## MyABDR update

*From the HFA and National Blood Authority MyABDR Team*



### WHAT'S NEW?

A new version of the MyABDR app was released on 1 March 2016. The major improvements and features included in the update are as follows:

- Significantly reduced synchronisation time for users of the mobile application
- The ability to request patient cards from the new **Request Patient Card** menu on the **Details** page in the mobile app
- Automatic syncing upon changing or uploading any data
- A pop up message to let users know if their new treatment or stock change will result in a negative stock balance
- A small indicator to let users know when a record is not successfully synchronised

Please ensure that you update your MyABDR app to take advantage of these new enhancements.

### USER TESTING AND FEEDBACK

In January 2016 a group of MyABDR users generously volunteered their time to test the latest update to the app. The feedback received was generally positive with most testers noting the improved syncing.

Do you have any feedback to give regarding MyABDR? We are constantly looking for ways to improve the system so if you have something to share please contact the MyABDR Support Team on the details below.

### OFFLINE MODE AND SECURITY

Offline mode is a feature within the MyABDR app which enables users to access their account and view and enter records while not connected to a network. The purpose of this function is to allow users to keep up to date with their treatment or product entries when unable to access a network. When back in range of a network, the entries made in offline mode will sync and update your account. **Please note, offline mode is accessible from the log in screen and does not require password authentication to gain access to your account. Therefore it is very important that users secure access to their smartphone via a pin, password or fingerprint scan to ensure their MyABDR data is secure.** Please refer to your phone's user manual to update your security settings.

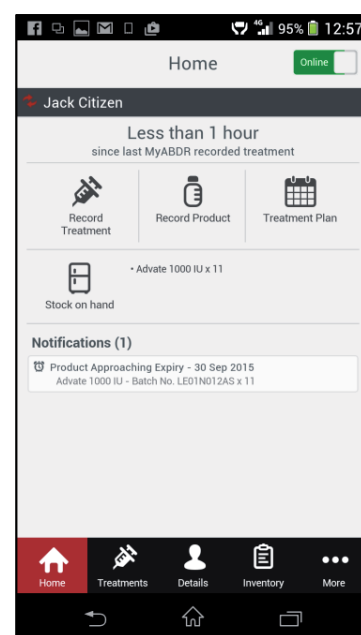
### NEED HELP?

Please do not hesitate to contact the MyABDR Support team if you have any question or concerns. Meghan, Danny, Andrew or Rebecca will be available and happy to assist you.

T: 13 000 BLOOD / 13 000 25663

E: [myabdr@blood.gov.au](mailto:myabdr@blood.gov.au)

Available 24 hrs a day, 7 days a week.







*With the WFH 2016 World Congress commencing next month our staff are keeping a keen eye on the WFH website for updates on keynote speakers and the topics that will be presented. Here is a glimpse of what is in store. The WFH website should be updated regularly during the congress so will be worth checking for new information in the world of haemophilia and related bleeding disorders. Below is a glimpse of what is on the program.*

#### **“Haemophilia Treatment in 2030”**

**Erik Berntorp, MD, Ph.D, Lund University and Malmö Centre for Thrombosis and Haemostasis.**

Plenary description: Hemophilia replacement therapy started in the 1950s and was rapidly developed during the coming decades. However, a severe backlash came when the community was exposed to hepatitis and HIV during the tainted blood scandal in the early 1980s. Due to the focus on developing safe products, the treatment modalities rendered less attention and the pace of improvement of care was slowed down. When safe concentrates became available and recombinant products were developed and came into the market about 25 years ago, this allowed the scientific and research community to direct their attention towards spread and development of prophylaxis.

However, remaining issues with inhibitors and the fact that a majority of PWHs in the world, if at all diagnosed, still do not get appropriate treatment have prompted development of long acting concentrates, by-pass therapy, and new treatment principles such as gene therapy, modifications of activation, and control of the clotting system. With an ever increasing knowledge of clotting factor immunogenicity, we are now approaching the coming decades with a broad array of tools at our disposal, with the potential to meet the need of each patient by 2030.

#### **“Hemophilia: Model of Patient Partnership and Healthcare”**

**Vincent Dumez, M. Sc., Co-director, Office of Collaboration and Patient Partnership, Faculty of Medicine, University of Montreal, Canada**

Plenary description: Many health-system leaders and stakeholders are advocating for contemporary medicine that fully engages patients as active partners in care. Establishing successful partnerships between patients, families and healthcare professionals is certainly one of the most promising lever of change, with the capacity to make significant improvements to care processes and

patient and family-related outcomes (e.g., quality of life). Yet, a gap persists between rhetoric and reality. A paradigm shift is necessary, but this shift must be initiated in difficult clinical contexts that are exacerbated by growing demands on healthcare systems and scarce resources.

The Faculty of Medicine at the University of Montreal has taken bold steps to trigger this important patient-partnership shift. The Faculty of Medicine is promoting a vision of medicine where patients, families and healthcare professionals redefine their relationship and jointly deal with pressing healthcare challenges. Efforts are now underway to nurture patient partnerships in three key domains: health sciences teaching, healthcare research, and care provision. These efforts build on significant cultural changes that have been initiated a long time ago by haemophilia clinics and communities

#### **“Excessive Bleeding in Women: Spotlight on Hemophilia Carriers”**

**Michelle Sholzberg, MD, FRCPC, Medical Director, Coagulation Laboratory, St. Michael’s Hospital, Toronto, Canada**

Plenary description: Bleeding disorders are difficult to diagnose and not often suspected in women, even though one in 100 people carries an inherited bleeding disorder gene. This plenary will review the multifaceted impact of excessive bleeding in women; the unique needs of women affected by excessive bleeding - need for a change in culture?; current management practices and future directions for women with inherited bleeding disorders; and explore the question: Hemophilia carriers, does the word carrier do a disservice to affected women?

[www.wfh.org](http://www.wfh.org)

## our community

HFV Members, family and friends,  
we need your helping hand.....



A sub-committee has been established to raise funds for projects and programs to meet our community needs.

We would like to invite you to be PART of this sub-committee by contributing to the organisation of a Charity Ball to be held in 2017.

If you would like to be part of our team please call  
Catherine on 0417 575 386

### YOUR PERSONAL STORIES

We often receive positive feedback about our newsletter. This is usually in relation to the personal stories that are often included. These stories always have an impact on our readers as our members can often relate in some way to that journey, understand the challenges faced and the highs and lows of living with a bleeding disorder, either personally or through a family member.

If you can spare some time please either put pen to paper or call me, we can chat over the phone and I can do the writing for you.

So please share your stories by forwarding them to [julia@hfv.org.au](mailto:julia@hfv.org.au) or call me on 9555 7595 — your stories really do add a personal perspective to our magazine and help to keep us connected.

**HFV Annual Membership Subscription Renewals have been included with this newsletter.**

**Payments are due by 30th June 2016.**

If you would prefer to complete your subscription online there is an editable PDF version of the form available on our website ([www.hfv.org.au](http://www.hfv.org.au)) which can then be emailed to [info@hfv.org.au](mailto:info@hfv.org.au)

Payment can also be made via direct deposit to BSB 033 063 Acc No 116909

*Your on-going membership gives HFV a stronger voice and enables us to support, connect and empower our community. Thanks for your support.*



## HAEMOPHILIA CENTRES

### HENRY EKERT

#### HAEMOPHILIA TREATMENT CENTRE

Royal Children's Hospital  
Flemington Road, Parkville  
P. (03) 9345 5099  
E. [he.htc@rch.org.au](mailto:he.htc@rch.org.au)

Dr Chris Barnes | Director Henry Ekert HTC  
Janine Furmedge | Clinical Nurse Consultant  
Julia Ekert | Office Data & Product Manager  
Nicola Hamilton | Physiotherapist

### RONALD SAWERS HAEMOPHILIA CENTRE

The Alfred  
1st Floor, Sth Block -William Buckland Centre  
Commercial Road, Melbourne 3004  
P. (03) 9076 2178  
E. (03) [haemophilia@alfred.org.au](mailto:haemophilia@alfred.org.au)

Dr Huyen Tran | Director of RSHC  
Penny McCarthy | Clinical Nurse Consultant  
Megan Walsh | Clinical Nurse Consultant  
Susan Findlay | Secretary  
Alex Coombs | Haemophilia Social Worker  
Jane Portnoy | Hepatitis C & Haemophilia  
Social Worker  
Abi Polus | Physiotherapist

**Anthony De Leo is working on a new event for HFV Dads and will be held in the city in October 2016 (TBC).**

**More info to follow in the September edition of our magazine and on our website. [www.hfv.org.au](http://www.hfv.org.au)**

**If you would like more info or to help Anthony organise this event please contact him directly on 0402 046 422.**

## HFV MEMBER SERVICES

### Membership Fees:

Standard family membership	\$33.00
Concession member	\$16.50
Allied Member	\$16.50
Organisational member	\$55.00

\* No joining fee for new members joining at the Standard Family Membership rate.

### Ambulance Subscription Subsidy:

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee. (Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

### To obtain an Ambulance Subsidy:

Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

### Other Subsidies:

SOS Talismans are available for purchase for \$15.00 from the office.

MedicAlerts: A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to \$30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

### Care and Counselling:

This is available through your treatment centre.

### Magazine:

Your quarterly magazine offers information and details of upcoming events.

### Website - [www.hfv.org.au](http://www.hfv.org.au)

The new HFV website is now online. It provides information, details of upcoming events and more. The site is updated weekly.

### The HFV Office:

The office is usually open from 8.30 am to 4.30 pm Monday to Thursday. If you plan to come to the office, we suggest you ring ahead to check if the office is staffed.

### We are located at:

13 Keith Street,  
Hampton East, Victoria, 3188.

Phone:	(03) 9555 7595
Fax:	(03) 9555 7375
Website:	<a href="http://www.hfv.org.au">www.hfv.org.au</a>
Email:	<a href="mailto:info@hfv.org.au">info@hfv.org.au</a>



**FACTORED IN**

[WWW.FACTOREDIN.ORG.AU](http://WWW.FACTOREDIN.ORG.AU)

Created by young people, for young people, to talk  
about life, being young and having a bleeding disorder.