

# National Haemophilia

Haemophilia Foundation Australia

[www.haemophilia.org.au](http://www.haemophilia.org.au)

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## TREATMENT FOR ALL THE VISION OF ALL



WORLD  
HEMOPHILIA DAY  
2016 | APRIL 17

Globally 1 in 1,000 people  
 has a bleeding disorder  
 most are not diagnosed and  
 do not receive treatment



TOGETHER WE CAN CHANGE THAT

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# WORLD HAEMOPHILIA DAY 2016



Every April 17, World Haemophilia Day is recognised worldwide to increase awareness of haemophilia and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH) which chose to bring the community together on April 17 in honour of WFH founder Frank Schnabel's birthday.

**In 2016 HFA will celebrate World Haemophilia Day to support the WFH goal of Treatment for All.**

### Light it Up Red!

Once again, landmarks and monuments around the world will support World Haemophilia Day by changing their lighting red on April 17.

### Global Feast

On World Haemophilia Day why not participate in Global Feast to fundraise for Treatment For All. Invite your family,

friends and work colleagues to a meal and ask them to bring a donation instead of flowers, wine or a gift.

**It's so easy, when you think about it, but it will make a huge difference to the lives of others.**

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

**Keep an eye on our website and Facebook page for information on events and happenings.**

There will be special activities for our online community, so be sure to follow these pages for details on World Haemophilia Day news and activities:

- WFH World Hemophilia Day page – [www.wfh.org/whd](http://www.wfh.org/whd)
- WFH Facebook page - [www.facebook.com/wfhemophilia](http://www.facebook.com/wfhemophilia)
- HFA's Facebook page - [www.facebook.com/HaemophiliaFoundationAustralia](http://www.facebook.com/HaemophiliaFoundationAustralia). #

Gavin Finkelstein is President, Haemophilia Foundation Australia



# FROM THE PRESIDENT

Gavin Finkelstein

## WORLD CONGRESS

The 2016 WFH World Congress will be held in Orlando, USA July 24 – 28, 2016.

For many in the Australian bleeding disorders community, the 2014 Congress in Melbourne was their first taste of this very important international meeting. It was extra special that the meeting was in Australia as it became accessible to so many more Australians - 400 amongst the 4000 delegates!

But two years has passed and the World Federation of Hemophilia is working with our friends from the National Hemophilia Foundation (NHF) in the USA towards what is promised to be a larger meeting than ever before. We look forward to a good meeting – and the opportunity to hear from leading scientific, medical and psychosocial experts, as well as patient community members who will share their experiences.

## COMMUNITY VOICE IN RESEARCH

The community's voice is critical.

It is also great to see that there is a worldwide effort to build the voice of the community into research. It is critical that research about treatment includes measures of the outcomes of treatment from the patient's point of view, and that of his or her family. For example, the right type of

evidence needs to be collected to demonstrate the value of new treatment therapies such as the longer acting clotting factor products which are becoming available around the world.

I have no doubt there will be strong discussions about published clinical trial and other research data at the Congress. This is timely for HFA as we are currently reviewing the HFA Treatment Policy to include the community's position about longer acting factors. But what is most important to us as a community organisation is to make sure that those issues relating to longer acting factors that are priorities for our community members are reflected in our Treatment Policy. We will continue to work on this with our community members; and we look forward to seeing what evidence-based data to support this arises at the Congress. **H**

A promotional graphic for the WFH 2016 World Congress. It features a circular logo on the left with the text 'WFH 2016 WORLD CONGRESS' and 'Orlando, USA - July 24-28' below it. To the right of the logo, the text reads 'THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY'. At the bottom, there is a QR code, the website 'www.wfh.org/congress', and logos for the National Hemophilia Foundation and the World Federation of Hemophilia (WFH).

# HFA UPDATE

Sharon Caris

## What do South Australians with bleeding disorders want from HFA?

We have reported our 2016 Community Survey from a national point of view, but we are currently analysing the responses of South Australians who completed the Survey to understand their preferences.

We received 29 South Australian responses, which represents about 15% of all, with men and women equally distributed. 75% of all said they lived in Adelaide. Interestingly 48% were aged between the ages of 31-54 and a further 47% were older than 55. Over half said they had a bleeding disorder, and a third said they were carriers of the haemophilia or VWD gene. Over a third were either a parent of a child with a bleeding disorder or a family member or carer.

There are some very helpful suggestions amongst the responses including whether there is more HFA can do to connect with people in country South Australia and recommendations for an annual social gathering for the community. The responses about the type of information people would like to receive about bleeding disorders were valuable – some people were keen for more information about parenting, sport and exercise, growing older, and treatment issues relating to inhibitors and treatment for von Willebrand disorder and new treatments for haemophilia.

Thank you for your participation, as it will be very helpful as we consider the next steps with our South Australian volunteers and health professionals. ■

# TEAM.FACTOR 2016

On Friday 22 January 2016 a group of cyclists led by Dr Simon McRae and Andrew Atkins rode as Team.Factor in the BUPA Challenge Tour in South Australia for the fourth year running. Team.Factor were fundraising for their favourite cause – Haemophilia Foundation Australia.

The BUPA Challenge Tour allows regular cyclists to ride the same Stage 4 route as the elite cyclists in the Santos Tour Down Under. In 2016 the route was from Norwood to Victor Harbor, over 140kms, including a punishing King of the Mountain climb up Crows Nest Road near Port Elliott.

This year Team.Factor increased to 10 members: Dr Simon McRae, Dr Uwe Hahn, Dr Tina Noutsos (Darwin), Dr Kobie Von Wielligh, Eric Von Wielligh, Cameron Cramey, Dan Drake, Andrew Atkins, Jaymie Clausen, Alex Nicholson and Abhi Phatak. Some of the team you may know from the South Australian Haemophilia Centre or the Royal Adelaide Hospital.

Haemophilia Foundation Australia thanks the team for their mighty effort. Also, a thank you to those who made donations and supported the team. The team has raised \$3,026.25 – just over their \$3,000 target. What a fantastic effort!

*“A really good ride this year – the start from Norwood to Norton Summit got us warmed up quickly, but riding through the Adelaide hills is always a great experience. The route took us through enough flat and downhill*

*sections to rest the legs, though the King of the Mountain after 120kms was pretty tough.”*

Andrew Atkins

*“Despite the threat of morning thunderstorms, conditions were dry and temperatures thankfully cool for the start of the ride. The initial climb up to Norton Summit rewarded everyone with views of the city, if you weren't too busy looking at the backside of the rider in front of you. Things were literally downhill from there for the next 100 km until we were confronted by Crows Nest Road 20 km from the finish that broke even the strongest of hearts. Despite this all riders on the team made it to the end. It was great fun and I am sure we will be back next year. Thanks for all the support and to everyone who contributed to raising for funds for the worthy cause of HFA.”*

Dr Simon McRae ■



This article was originally published on *The Conversation*, 7 August 2012 <<http://theconversation.com/pain-really-is-in-the-mind-but-not-in-the-way-you-think-1151>> and is reprinted with permission

## THE CONVERSATION

Lorimer Moseley is Professor of Clinical Neurosciences and Chair in Physiotherapy, University of South Australia

# PAIN REALLY IS IN THE MIND, BUT NOT IN THE WAY YOU THINK

*Lorimer Moseley*

Prof Lorimer Moseley's presentation on pain at the Gold Coast Haemophilia Conference raised a lot of interest. In this article he explains the background to current understandings in pain science.

Everybody hurts, but not everybody keeps hurting. The unlucky few who do end up on a downward spiral of economic, social and physical disadvantage.

While we don't know why some people don't recover from an acute episode of pain, we do know that it's not because their injury was worse in the first place. We also know that it's not because they have a personality problem. Finally, we do know that, on the whole, treatments for chronic pain are not particularly successful.

This sobering reality draws up some interesting reflections on pain itself. What is pain? Is it simply a symptom of tissue damage or is it something more complex? One way to approach this second question is to determine whether it's possible to have one without the other – tissue damage without pain or pain without tissue damage.

And you can answer that one yourself – ever noticed a bruise that you have absolutely no recollection of getting? If you answered yes, then you have sustained tissue damage without pain. Ever taken a shower at the end of a long day in the sun and found the normally pleasantly warm water, painfully hot? That's not the shower injuring you - it's just activating sensitised receptors in your skin.

Such questions and their answers are of great interest to pain scientists because they remind us that pain is not simply a measure of tissue damage.

### WHAT IS PAIN?

The International Association for the Study of Pain defines pain as an experience. Pain is usually triggered by messages that are sent from the tissues of the body when those tissues are presented with something potentially dangerous.



Prof Lorimer Moseley explaining pain at the Gold Coast Conference

“The idea that an inaccurate understanding of chronic pain increases chronic pain begs the question - what happens if we correct that inaccurate piece of knowledge?”

The neurones that carry those messages are called nociceptors, or danger receptors. We call the system that detects and transmits noxious events “nociception”. Critically, nociception is neither sufficient nor necessary for pain. But most of the time, pain is associated with some nociception.

The exact amount or type of pain depends on many things. One way to understand this is to consider that once a danger message arrives at the brain, it has to answer a very important question: “How dangerous is this really?” In order to respond, the brain draws on every piece of credible information – previous exposure, cultural influences, knowledge, other sensory cues – the list is endless.

How might all these things modulate pain? The favourite theory among pain scientists relies on the complexity of the human brain. We can think about pain as a conscious experience that emerges in response to activity in a particular network of brain cells that are spread across the brain. We can call the network a “neurotag” and we can call the brain cells that make up the neurotag “member brain cells”.

Each of the member brain cells in the pain neurotag are also member brain cells of other neurotags. If we have the phrase “slipped disc” in our brain for instance, it has to be held by a network of brain cells (we can call this the “slipped disc” neurotag). And it’s highly likely that there are some brain cells that are members of both the slipped disc neurotag and the back pain neurotag. This means that if we activate the slipped disc neurotag, we slightly increase the likelihood of activating the back pain neurotag.

Using this model, thinking that we have a slipped disc has the potential to increase back pain. But what if this piece of knowledge we have stored is inaccurate, just like our notion of a slipped disc? A disc is so firmly attached to its vertebrae that it can never, ever slip. Despite this, we have the language, and the pictures to go with it, and both strongly suggest it can.

When the brain is using this inaccurate information to evaluate how much danger one’s back is in, we can predict with confidence that, if all other things were equal, thinking you have a slipped disc and picturing one of those horrible clinical models of a slipped disc will increase your back pain.

#### **SELF-PERPETUATING PAIN**

This is where our understanding of pain itself becomes part of a vicious cycle. We know that as pain persists the nociception system becomes more sensitive. What this means is that the spinal cord sends danger messages to the brain at a rate that overestimates the true danger level.

This is a normal adaption to persistent firing of spinal nociceptors. Because pain is (wrongly) interpreted to be a measure of tissue damage, the brain has no option but to presume that the tissues are becoming more damaged. So when pain persists, we automatically assume that tissue damage persists.

On the basis of what we now know about the changing nervous system, this presumption is often wrong. The piece of knowledge that’s turning up the pain neurotag is actually being reinforced by itself! I think it goes like this: “more pain = more damage = more danger = more pain” and so on and so forth.

The idea that an inaccurate understanding of chronic pain increases chronic pain begs the question - what happens if we correct that inaccurate piece of knowledge?

We’ve been researching the answer to this for over a decade, and here’s some of what we’ve found:

- (i) Pain and disability reduce, not by much and not very quickly but they do;
- (ii) Activity-based treatments have better effects;
- (iii) Flare-ups reduce in their frequency and magnitude;
- (iv) Long-term outcomes of activity-based treatments are vast improvements.



There's compelling evidence that reconceptualising pain according to its underlying biology is a good thing to do. But it's not easy. Our research group is continually looking for better ways of doing this, and we're not the only ones. The idea of explaining pain has taken off in pain management programs and outpatients departments the world over.

### CLINICIANS NEED TO RETHINK TOO

"For example, if the fire A is close to the foot B, the small particles of fire, which as you know move very swiftly, are able to move as well the part of the skin which they touch on the foot. In this way, by pulling at the little thread cc, which you see attached there, they at the same instant open e, which is the entry for the pore d, which is where this small thread terminates; just as, by pulling one end of a cord, you ring a bell which hangs at the other end.... Now when the entry of the pore, or the little tube, de, has thus been opened, the animal spirits flow into it from the cavity F, and through it they are carried partly into the muscles which serve to pull the foot back from the fire, partly into those which serve to turn the eyes and the head to look at it, and partly into those which serve to move the hands forward and to turn the whole body for its defense"  
Descartes, *On Man*, 1662

From René Descartes' *Traite de l'homme*/Wikimedia Commons



What we know about how pain works is not just relevant to how we teach it to patients; we need to base our clinical decisions on it. This means abandoning Rene Descartes' famous model of 1654. His drawing depicts a man with his foot in the fire and a "pain receptor" activating a hydraulic system that rings a bell in his head. Of course no one believes we have hydraulics making this happen, but the idea of an electrical circuit turning on the pain centre is still at the heart of many clinical practices across professional and geographic boundaries.

The type of thinking captured in Descartes' model has led to some amazing advances in clinical medicine. But the evidence against it is now almost as compelling as that against the world being flat.

Of course, those sailors who never leave the harbour might hang on to the idea of a flat world. And, in the same way, there are probably clinicians who hang on to the idea of pain equalling tissue damage. I suspect they either don't see complex or chronic pain patients, or, when they do, they presume that those patients are somehow faulty or psychologically fragile, or, tragically, are lying.

Perhaps they can continue to practice without ever leaving the harbour. The problems I want to solve clearly exist on the open seas. ■

# BALANCE, BONE DENSITY AND FALLS:

Rebecca Dalzell

## THE FACTS

No one wants to be called 'old'! Most of us feel young at heart and hate to consider that our bodies are experiencing anything different! Unfortunately once we pass early adulthood we are all in a gradual state of decline. Even before we feel it, we are beginning to wear out. Our joints deteriorate, our muscles don't work as well as they used to, our balance declines and our bones become less dense. These are unavoidable facts! For many, this decline slips by unnoticed for many years, until it suddenly starts to become apparent in later life. For others, including those with bleeding disorders, the starting point is often compromised, and the signs of this process can begin to present themselves earlier... Let me explain.

People with bleeding disorders have been shown to have poorer balance when compared to others of the same age, and this begins in childhood. Joint bleeds and joint damage can alter what is called **proprioception** (our awareness of where our body is in space) and this, among other factors, can contribute to decreased balance reactions. Many may not be aware of this deficit, or the need to address it – until it's too late!

Bone density in those with severe bleeding disorders has also been shown to be decreased, beginning in childhood, when compared with controls. There are numerous possible contributing factors here including:

- Prolonged periods of immobilisation during childhood and adolescence (a lack of weight bearing activity in this time leads to a decreased peak bone mineral density or **BMD**)
- Significant arthropathy (bleed related joint damage)
- Lack of prophylaxis
- Exposure to hep C and HIV.

Decreased BMD may initially be asymptomatic, but ongoing decline can lead to **osteoporosis** and increased risk of fracture. These factors, along with haemophilia-related joint damage, pain, and decreased joint range of motion, mean that those with bleeding disorders are at increased risk of falls and fracture (even though they may not know it) – and this can have serious consequences.

Studies done in the general population show that 30% of those over 65, and 50% of those over 80 fall each year. 20-30% of those in the general population who fall suffer injuries that reduce mobility and independence and increase the risk of premature death. For those with bleeding disorders these statistics would most likely be higher due to the presence of additional falls risk factors.

## THE GOOD NEWS

It's not all bad news. Your Haemophilia Treatment Centre Physiotherapist can help! There are a huge range of activities you can do with your Physiotherapist to help improve balance, optimise BMD, prevent falls and enhance quality of life. Many of these problems can be averted.

Physical activity has been shown to have numerous benefits. Research shows that balance can be improved, and most falls prevented, through physical activity. Exercise programs that address strength, balance, flexibility and/or endurance (2-3 of these components) have been shown to significantly reduce the rate of falls, and the number of people falling.

BMD can also be positively influenced by exercise. For those who are younger – teens to early twenties – exercise can significantly help to build strong bones to optimise peak BMD (giving you a much better starting point for the rest of your life!). For those who are more mature, it has been shown that BMD can be maintained, if not slightly improved, and bone turnover decreased, through strength training and weight bearing exercise<sup>3</sup>. Hip fractures have been found to be nearly half as frequent in adults who have been physically active in their daily life compared to less active people.

Physical activity also helps reduce pain, improve joint nutrition, strengthen muscles, improve joint stability, preserve and possibly improve joint range of movement, assist in weight control, improve posture, and prevent secondary musculoskeletal complications. These all help to maintain function and prevent many of the associated adverse health outcomes.

There are also many health and environmental factors that can both optimise BMD, and reduce falls risk, significantly reducing the risk of fracture. These will be explained further below.



# A NOTE FOR THE NOT SO OLD.....

## ACTION PLAN: PREVENTION IS THE BEST MEDICINE

### Participate in physical activity throughout life

- Best if started early and continued throughout life. Short term 'boom and bust' programs have little long term benefit
- Make it a lifestyle choice and find ways to incorporate 'incidental' activity into your day, eg pulling or pushing, using the stairs, or not using the remote for the TV (every little bit of movement helps!)
- Find activities you enjoy
- Set goals
- Exercise with a friend
- Include activities that challenge your **balance**, eg. the **Strong Bloody Men** program (Qld), or Tai Chi as seen on the **Inspire** DVD (available through HFA), or Pilates classes
- Include weight bearing and resistance activities for bone health
- Talk to your physiotherapist if you need help getting started, or you want some ideas of what might be best for you.

### General health issues (talk to your GP)

- Regular vision checks – declining vision increases falls risk
- DEXA scans to assess BMD (as appropriate). Indicated routinely if you are over 70 years or have a previous fracture, or advised if there are significant other predisposing factors
- Calcium – important for good bone health. Ensure adequate dietary intake (at least 1,200 mg per day), and discuss supplements with your GP as appropriate
- Vitamin D – also important for bone health. Small amounts of daily sun exposure helps in maintaining healthy levels of vitamin D
- Discuss pharmacological interventions with your GP, eg bisphosphonates or calcitonin, as required
- Avoid tobacco smoking and excessive alcohol intake (negatively impacts on bone health among other things!)

### Environmental issues

- Ensure a safe home environment – remove trip hazards, install rails, de-clutter, etc
- Install good lighting for better visibility
- Use walking aids or assistive devices for safety when required.
- Wear safe and supportive footwear.

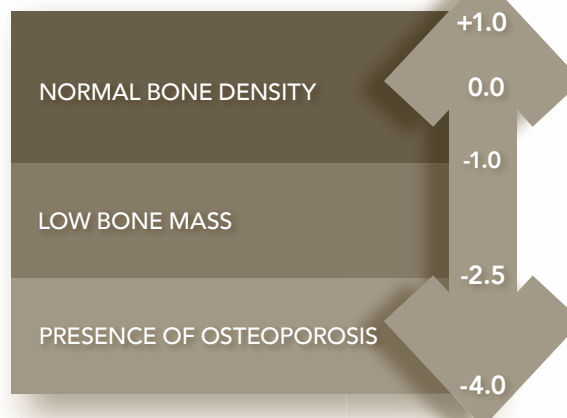
### FOR MORE INFORMATION

- Osteoporosis Australia - [www.osteoporosis.org.au](http://www.osteoporosis.org.au)
- Look up your local state's falls guidelines, eg **Stay on your feet** (Qld), or **Your home safety checklist** (WA)
- Contact your Haemophilia Treatment Centre including the Haemophilia Physiotherapist
- Talk to your GP for general health issues and relevant investigations. **H**

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### T-SCORE



# HAEMATURIA (BLOOD IN THE URINE)

*Megan Walsh*

Blood in the urine (haematuria) can be frightening and it is the one condition that does prompt people with haemophilia to ring their Haemophilia Treatment Centre for advice.

If the blood in the urine is obvious to the naked eye it is called "macroscopic" or "visible haematuria". If the blood can only be detected with laboratory testing it is called "microscopic" or "non-visible". Blood in the urine is a fairly common problem in the general population. Up to 16% of young adults experience it and around 21% of men over 50 will experience it at some time.

It is a fairly frequent occurrence also in people with haemophilia. It has been reported that up to 66% of people with haemophilia have experienced haematuria at some time.

The urine can be red or brown in colour, but that doesn't reflect how much blood is being lost: as little as 1 ml of blood in 1 litre of urine can cause it to change colour. The urine can often be darker brown in the morning as it has been concentrated overnight and it becomes redder during the day.

The bleeding may arise from any part of the urinary system from the kidneys to the bladder and prostate.

## CAUSES

There may be many causes of haematuria. Infection is the most common cause; other common causes include small kidney stones passing, vigorous exercise or sexual activity, certain medications, or trauma/injury to the area. It can also be a symptom in older men who have an enlarging prostate, but no cancer.

Very rarely it may be associated with cancer of the bladder, kidney or prostate.

## TREATMENT

Although you are normally advised to treat at the first sign of a bleed in this case the advice is different.

**DO NOT TREAT** either with factor concentrate or tranexamic acid tablets.

## Talk to your Haemophilia Treatment Centre.

This is important because you do not know where the bleeding is coming from. Treating may cause a large clot to form and block the kidney or ureter (tubes taking urine from kidney to bladder), causing pain and damage to the kidney. It may cause clots to form in the bladder preventing the passing of urine.

You are advised to rest, with no straining or lifting or rushing around.

Increase your fluid intake 2-3 litres per day, but avoid acid drinks like orange juice, tomato juice or highly sugared drinks like lemonade/coke.

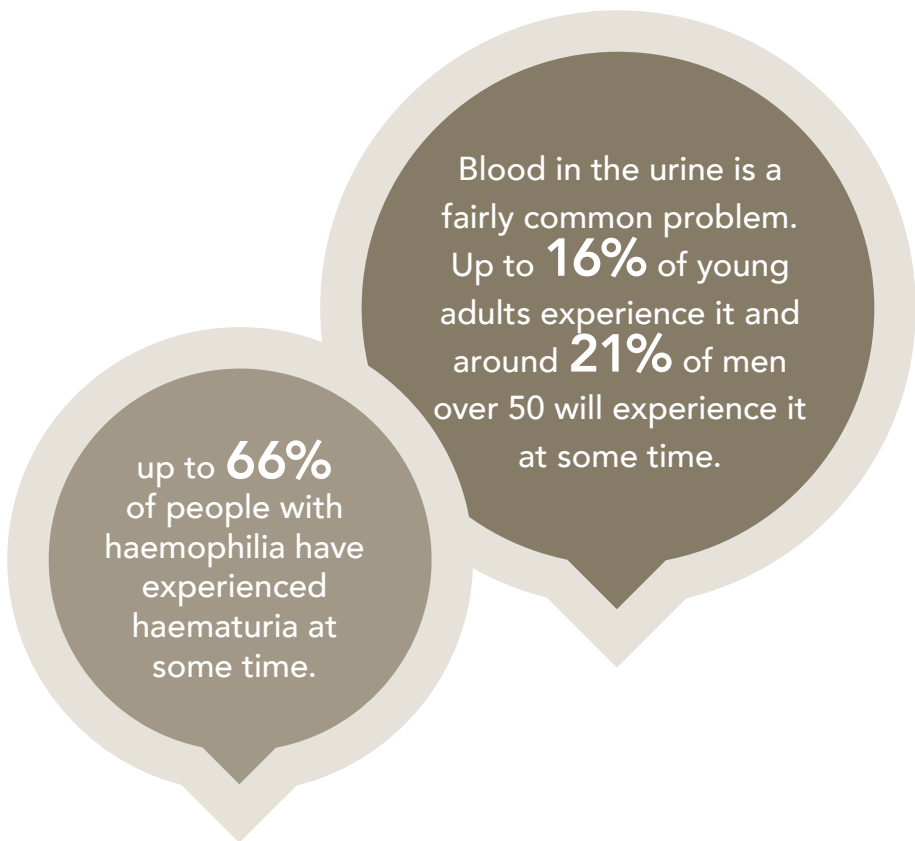
Avoid coffee and alcohol.

If you have burning, try using a urinary alkaliser (available over-the-counter from the pharmacy – ask your pharmacist about the different brands) to help make the urine more alkaline.

Discuss what to do with your Haemophilia Treatment Centre. If you have no pain anywhere, no burning on passing urine and are feeling well, and have no history of trauma/injury to the area, no smelly urine, and are not passing clots, it may be appropriate to rest at home with increased fluid intake, and the haematuria usually resolves in 1-3 days. If it does not get better, you may need to come in to hospital to have some intravenous fluids to help flush your urinary system.

Go to a doctor immediately if you experience:

- Pain in the back, sides or abdomen
- Clots



- Increased blood in your urine
- Smelly urine/cloudy urine
- Pain, burning when passing urine
- Feeling unwell, feverish, high temperature
- Or you have had injury to the area around kidneys and now have haematuria.

**TESTS**

- Usually a urine sample is taken and sent to the laboratory for testing to see if there are any bacteria in the urine. If any are found you would be started on antibiotics
- If you have a lot of clots and blood in urine, a blood test would be done to check that you have not lost too much blood
- Any pain would require a scan: either ultrasound or CT scan
- Sometimes a follow up cystoscopy may be required (camera scope to look into the bladder)
- A pyelogram may also be used to investigate further if you have had a few episodes of haematuria (intravenous contrast is injected and is excreted by the kidneys, so a picture of the whole urinary system can be obtained)
- If you have more than one episode of haematuria, you will be referred to a urologist as a precaution to have a further check
- If you are older than 40 you will be referred to a urologist after the first episode of haematuria for a further check.

In rare cases when the haematuria continues and no cause (i.e., infection etc.) can be found, some low dose factor concentrate may be used, but this would be in a hospital situation and in conjunction with intravenous fluids to flush the kidneys.

**IN CONCLUSION**

Haematuria occurs not infrequently in people with haemophilia. It is best not to treat, but you are advised to talk to your Haemophilia Treatment Centre to discuss your own particular medical condition and gain their advice.

Simple haematuria, with no signs of clots, pain, burning, temperature, smell should settle with simple measures such as rest, increased fluid intake in 1-3 days, but a phone call to your Haemophilia Treatment Centre is advised.

Any signs of pain, fever, illness, cloudy urine, or clots require immediate medical attention.

Haematuria occurring in men over 40 should be investigated further by a urologist.

Haematuria lasting more than a couple of days and occurring on several occasions requires investigation. ■

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# HEP C NEWS

## NEW HEP C TREATMENTS AVAILABLE

Very welcome news for our community arrived just before Christmas: on 20 December 2015 Australian Minister for Health Sussan Ley announced that new breakthrough hepatitis C treatments will be available on the PBS from 1 March 2016.

### The new hepatitis C medicines are:

- 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."

Most of these treatments can be taken orally as tablets, with the most common course of treatment being as short as 12 weeks.

"This combination of breakthrough cures has a success rate of more than 90 per cent across the entire hep C patient population and is faster and has fewer side effects than anything currently available," said Minister Ley.

Listing the new medicines on the PBS will mean that people with hepatitis C will only pay up to the normal PBS co-payment for these treatments: currently \$6.20 for concessional patients and \$38.30 for general patients each time the medicines are dispensed by the pharmacy.

"HFA will continue to work with expert health professionals and health services to make sure that people with bleeding disorders can access treatment when needed in a timely manner," noted Gavin Finkelstein. "For our community members, the message about being proactive with your hepatitis C care is even more important now: look after your liver health, make

## WHAT'S NEW

- New hep C treatments available on the PBS from 1 March 2016
- Very successful and few side effects
- Mostly interferon-free – just tablets
- For people with cirrhosis and previously unsuccessful treatment too
- Don't wait – make an appointment now with your hepatitis or HIV clinic!
- And talk to your Haemophilia Centre too

sure you have had your liver health checked and talk to your hepatitis or HIV clinic about your treatment options."

## WHAT NEXT?

It is a very exciting time for hepatitis C, and with more developments likely in the future.

## What's different about these treatments?

These new treatments provide very successful cure rates for nearly all genotypes. However, the treatment combinations and the length of treatment will be very individual. They will depend on factors such as the person's genotype, whether they have had unsuccessful treatment before, whether they have cirrhosis, and other issues.

For example, although most people may be able to have interferon-free treatments, some may need to have a combination treatment with ribavirin. Others, including those with genotype 4 and 6, may need to have a combination treatment with sofosbuvir and pegylated interferon and ribavirin. Some may need 12 weeks of treatment; others may need 24 weeks.

More detailed medical treatment protocols have been developed by hepatitis and infectious diseases specialists. These define the tests required, when they should be administered, the different treatment regimens, and what the treating doctor needs to consider and monitor. Until these protocols are implemented nationally, this may vary among the specialist clinics. In any case, some people may need to be managed and monitored more closely than others because of their particular health issues or complications.

## Who will be able to prescribe treatment?

As with the previous hepatitis C treatments, gastroenterologists, hepatologists and infectious diseases specialists experienced in treating hepatitis C are able to prescribe the new treatments.

A major new step is that processes are being set up for general practitioners (GPs) to prescribe hepatitis C treatments in the future as well. This will include a national medical education program and may take some time to establish across Australia. While most people with

“This combination of breakthrough cures has a success rate of more than 90 per cent across the entire Hep C patient population and is faster and has fewer side effects than anything currently available,” said Minister Ley.

bleeding disorders will attend their specialist hepatitis or infectious diseases clinic for hepatitis C treatment, this may be of interest to some people who have difficulty accessing specialist clinics; for example, in regional areas. We will keep you updated on progress.

Under the PBS listing, the treating doctor will need to have information on:

- the patient's HCV genotype
- whether they have cirrhosis or not, eg through a fibroscan test
- and evidence that they have chronic hepatitis C infection, eg if positive HCV antibody and HCV RNA PCR tests are documented in their medical record.

#### What if you have a bleeding disorder?

This situation is new and how it will work best for people with bleeding disorders needs to be looked at in more detail and understood.

HFA has had initial discussions with the Australian Haemophilia Centre Directors' Organisation (AHCDO) and hepatitis and HIV/HCV co-infection specialists. In the immediate future, the best course of action for people with bleeding disorders and hepatitis C is to make an appointment with their hepatitis/liver clinic - or, if they have HIV/HCV co-infection, their HIV or infectious diseases physician - and discuss their treatment options so that they can have a treatment regimen tailored to their particular health and situation. It is important also to touch base with their Haemophilia Centre to discuss referrals and make sure their Centre stays in the loop.

#### Treatments in the pipeline

Other treatments are also in the process of coming before the Pharmaceutical Benefits Advisory Committee (PBAC) for listing on the PBS:

- **Viekira Pak®** (for genotype 1) has been approved and is completing the process for listing on the PBS
- **Zepatier® (elbasvir/grazoprevir)** was to go before PBAC in March 2016, but this has been postponed by the pharmaceutical company producing it. Zepatier has had high success rates in people who have had unsuccessful treatment and in people who are HIV/HCV co-infected. It is also being trialled in people

with bleeding disorders. HFA is likely to make a submission in support of Zepatier when it comes before PBAC.

Clinical trials of other new hepatitis C treatments are continuing and we hope to see more highly successful treatments coming before PBAC in the next couple of years.

#### WHAT CAN YOU DO NOW IF YOU HAVE HEPATITIS C?

In the meantime - if you have hepatitis C and a bleeding disorder, remember that 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 advanced liver disease?** 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.

#### FURTHER READING

Read Minister Ley's Press Release – <http://tinyurl.com/hepctreatments-dec15>

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) ■

This factsheet is abridged and adapted from the original published by Hepatitis NSW (www.hep.org.au) on 9 February 2016. It is reprinted with permission.

# FACTSHEET: TREATMENTS FOR HEPATITIS C DIRECT ACTING ANTIVIRALS (DAAS)

For more information about anything in this factsheet, if you are in NSW, phone the NSW Hepatitis Infoline on 1800 803 990 or go to [www.hep.org.au](http://www.hep.org.au). If you are in other states, phone the National Hepatitis Information Line on 1800 437 222.

The information in this factsheet will be amended as new information emerges. In particular, the administrative details concerning prescription arrangements for GPs and other doctors still need to be established. New treatment consensus guidelines also are being developed. The purpose of this factsheet is to provide as much information about the new treatments as is currently known.

## INTRODUCTION

This year, 2016, is a particularly exciting time for the treatment opportunities for all people in Australia living with hepatitis C. It has been announced that new direct acting antiviral treatment drugs will be listed on the Pharmaceutical Benefits Scheme (PBS) on 1 March 2016.

This factsheet relates to these hepatitis C treatment combinations:

- **Harvoni® (sofosbuvir/ledipasvir)** two drugs combined in one pill, taken daily
- **Sovaldi® and Daklinza® (sofosbuvir and daclatasvir)** separate pills, taken daily
- **Sovaldi® and Ibravir® (sofosbuvir and ribavirin)** separate pills, taken daily

Other new drugs for treating hepatitis C are currently in different stages of development and/or approval. Over time, these new drugs will also likely be PBS listed and funded, and this factsheet will be amended accordingly.

## SUCCESS RATES OF THE NEW TREATMENTS

**sofosbuvir/ledipasvir** = around 95% of people (with genotype 1) achieved cure in Phase 3 studies (see "Defining cure", below, for an explanation of "cure").

**sofosbuvir and daclatasvir** = around 95% of people (with genotypes 1 or 3 and no cirrhosis) achieved cure in Phase 3 studies. People with genotype 3 and cirrhosis have lower (although still relatively high) cure rates and will require longer duration or addition of ribavirin.

**sofosbuvir and ribavirin** = around 93% of people (with genotype 2) achieved cure in Phase 3 studies.

The above cure rates relate to people's hepatitis C genotype and treatment history. They are from Phase 3 clinical trials (researching efficacy in large study groups) and therefore may not apply to real life. Treating doctors will advise which treatment options are suitable for individual people.

## TREATMENTS AND GENOTYPES

**Hep C genotype 1** = sofosbuvir/ledipasvir  
sofosbuvir and daclatasvir

**Hep C genotype 2** = sofosbuvir and ribavirin

**Hep C genotype 3** = sofosbuvir and daclatasvir

People with **genotypes 4 or 6** remain limited to sofosbuvir taken with pegylated interferon and ribavirin treatment (greater than 90% cure rate).

Other drug combinations are approved and available but those mentioned above are the ones with best response and tolerability.

## TREATMENT DURATIONS

**sofosbuvir/ledipasvir**

= 8 weeks for people with no prior treatment, no cirrhosis and viral load less than 6 million IU/mL

= 12 weeks for people with no prior treatment, no cirrhosis and viral load more than 6 million IU/mL

= 12 weeks for people with no prior treatment and cirrhosis

= 24 weeks for people with prior treatment and cirrhosis

**sofosbuvir and daclatasvir**

= 12 weeks (although likely longer for people with cirrhosis)

= 24 weeks for people with genotype 3 and cirrhosis

#### **sofosbuvir and ribavirin**

= 12 weeks for people with genotype 2

#### **sofosbuvir and daclatasvir and ribavirin**

= 12 to 16 weeks for people with genotype 3 and cirrhosis.

### **ARE NEW TREATMENTS TAKEN WITH RIBAVIRIN OR INTERFERON INJECTIONS?**

As listed above, sofosbuvir is sometimes taken with ribavirin. Also, sofosbuvir and daclatasvir may additionally be taken with ribavirin for those people who have genotype 3 and cirrhosis.

Importantly, all the new treatments are taken as tablets (pills) and none involve interferon injections.

(Treatment for people with genotypes 4 or 6 involves sofosbuvir taken with pegylated interferon injections and ribavirin tablets.)

### **TREATMENT SIDE EFFECTS**

**Sofosbuvir/ledipasvir** is well tolerated with only minor side effects.

**Sofosbuvir and daclatasvir** are well tolerated with only minor side effects.

**Sofosbuvir and ribavirin** are well tolerated (the most common adverse events of ribavirin are anaemia, fatigue, headache, skin irritation and insomnia).

### **TREATMENT CONTRAINDICATIONS**

There are some drug-drug interaction issues, including amiodarone (an antiarrhythmic medication used to treat ventricular tachycardia or ventricular fibrillation), but most issues will be able to be handled with change of accompanying medications, or through careful monitoring.

Pregnancy must be strictly avoided by both men and women treated with ribavirin in any of the treatment combinations (during treatment and for 24 weeks after). Pregnancy must also be avoided with daclatasvir (during treatment and for 5 weeks after). People should be advised to talk to their doctor or specialist about treatment with sofosbuvir/ledipasvir in pregnancy.

Treating doctors or specialists will advise which treatments would be suitable (or not suitable) for patients, depending on their past and present medical conditions and any other medications they are taking.

### **PREPARING FOR TREATMENT**

People with hepatitis C will have an initial GP or specialist assessment. This will involve full blood testing and likely assessment of their fibrosis stage, via Fibroscan®. People with cirrhosis will be referred for specialist care and treatment. People with cirrhosis require long term

monitoring for complications including liver cancer.

(Treatment protocols are currently in development and once they are confirmed, the information in this factsheet will be amended.)

### **TREATMENT MONITORING AND FOLLOW UP**

Treating doctors will probably use a week 4 PCR viral load test to assess treatment adherence as opposed to speed of viral load decline. By week 4, nearly all people are likely to be <1,000 viral load and generally <100 viral load, if they are taking the medication as prescribed.

Some hospital clinics may use different protocols based on whether or not people have other illnesses and the complexity of their hepatitis C disease.

People with no complicating factors may need to have only one on-treatment visit (generally at week 4). This would typically involve blood testing at week 4 for Full Blood Count, Urea & Electrolytes Test, Liver Function and PCR viral load (mentioned above). Some people will require more intensive monitoring/follow-up.

All people will require a PCR viral load test 12 weeks after treatment finishes to check if they are cured.

(Treatment protocols are currently in development and once they are confirmed, the information in this factsheet will be amended.)

### **DEFINING CURE**

“Cure” or “SVR” (Sustained Virological Response) means that someone has cleared hepatitis C virus from their body. If someone has a PCR viral load test which shows undetectable (no virus) at 12 weeks after treatment finished they are considered to be cured.

If hepatitis C has caused significant liver damage, clearing the virus (cure) might not mean that someone is healthy again all of a sudden. In particular, if someone has cirrhosis, they still need specialist care and monitoring. People with cirrhosis still have a potential risk of developing liver cancer, even after being cured of hepatitis C.

People should talk to their treating doctor about what “cure” should mean for them.

*This factsheet was developed by Hepatitis NSW. It was reviewed by the Hepatitis NSW Medical and Research Advisory Panel with special input from Prof Gregory Dore and A/Prof Simone Strasser.*

Last updated 9 Feb 2016 ■

# WFH GLOBAL FORUM

*Sharon Caris*

The World Federation of Hemophilia Global Forum held in November 2015 was packed full of information, in fact so much, that it was hard to keep up!

## **TREATMENT FOR ALL**

As always, it is confronting that despite increased global supply of recombinant clotting factors and some innovative humanitarian programs for plasma derived clotting factors, there remains significant unmet need in the developing world. With only 30% of the global haemophilia community accessing appropriate treatment, there is huge scope for both recombinant and plasma derived factor VIII, in particular, but the ongoing and huge challenge is to find ways and motivation for the manufacture and supply of treatment that is affordable and accessible to those who need it. It is our responsibility in Australia to try to do something about this, and I urge you to participate in activities that will help achieve the WFH vision, and ours, of **Treatment for All**.

## **TREATMENT SAFETY**

Safety is linked to supply. For those without access to a supply of safe treatment, there is a need for both of these aspects to be addressed. While the historical concerns about blood product safety are somewhat more reassuring now we have appropriate viral inactivation and donor selection strategies in place, there is no place for complacency – there are new viruses capable of emerging in biologicals at any time. Further, the ongoing challenge and worry remains the complication of inhibitors developing in people using clotting factor and whether these can be prevented or reversed. It is pleasing that there are new treatments in development and some not very far away from the market.

## **EVALUATING NEW PRODUCTS**

The discussions around new products and longer acting clotting factors and gene therapy are very interesting and challenging. There are more treatment products for bleeding disorders in various stages of development globally than ever before. The holy grail of gene therapy continues to be elusive on a large scale, although there have been some successes with small groups of patients.

There was great interest at the Forum in how to evaluate the benefits and costs of longer acting clotting factor therapies. Clotting factors with longer or extended half-lives stay at higher levels in the body for longer and less frequent/fewer infusions are needed to achieve the same clotting result as for the regular clotting factor products.

These new products have led to international and local discussion about how prophylaxis treatment should be given, what doses should be given, how often and what % clotting factor levels should be aimed for in a person's blood. Many agree there is potential for better treatment outcomes and better adherence to treatment. A prophylaxis protocol can be tailored to the individual based on his/her bleeding patterns and clotting factor levels as well as taking into account factors such as age, joint health, and physical activity.

## **PATIENT PARTICIPATION**

The benefits would need to be justified by governments who pay for treatment products, and the patient community will have an important role in providing some of the data on outcomes of such treatments for this. MyABDR could become a very important tool in Australia as the data generated from this helps doctors and their patients understand and evaluate the outcomes of treatment. The HFA Council is considering the HFA Treatment Policy in the context of longer acting clotting factors and other novel treatments and how these are evaluated in Australia for purchase and supply.

At the Forum, I reflected on the benefit for both clinicians and patients where clinical trials are available, and the value of more trials having been available in Australia in recent years. It is important for clinicians to have experience with a range of therapies, but our community also benefits from the courage of individuals who join clinical trials that later result in new products being manufactured, registered and ultimately available to others. Keep in touch with your Haemophilia Centre to hear about new opportunities for new treatments or clinical trials. ■



# PROBE STUDY



How can HFA and haemophilia organisations around the world 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.

In the future the PROBE study will cover the range of bleeding disorders. The initial stages of the survey (Phases 1 and 2) are testing the research methodology in haemophilia and allow people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. This data will be used to analyse the perspectives of people with haemophilia on outcomes that affect their own life and care. It is particularly important data to have when HFA tries to understand what the issues are for our community, and will enable us to quantify and represent these issues in a robust and credible way to our Council and others, such as governments or treatment and service funding bodies.

## 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 worldwide results were discussed:

- More than 700 surveys were completed by 15 countries
- Results demonstrated validity and that the research methodology was robust
- Phase 1 data is useful for understanding how to use the potential results but cannot be used for representation on health issues at this point – we need to wait for phase 3
- Australian feedback on questions was put in a spreadsheet and each comment was 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
- Some other small changes were made to the Australian version of the survey
- For good comparable data, in future Australia needs to recruit more people with moderate haemophilia to complete the survey.

A poster about Phase 1 was presented at the European Association for Haemophilia and Allied Disorders (EAHAD) Congress in Sweden in February 2016 and very well received.

## Phase 2

The next phase involves reproducibility – testing an online version of the survey as well, and retesting the same community (ie, Australia) twice in several months to see whether the results remain consistent. There will be more information about this soon. 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> #

# MYABDR UPDATE



From the HFA and National Blood Authority  
MyABDR Team

## NEW FEATURES!

- Better, faster syncing
- Option to request your patient wallet card
- Alert if your treatment stock is about to go negative.

## 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.

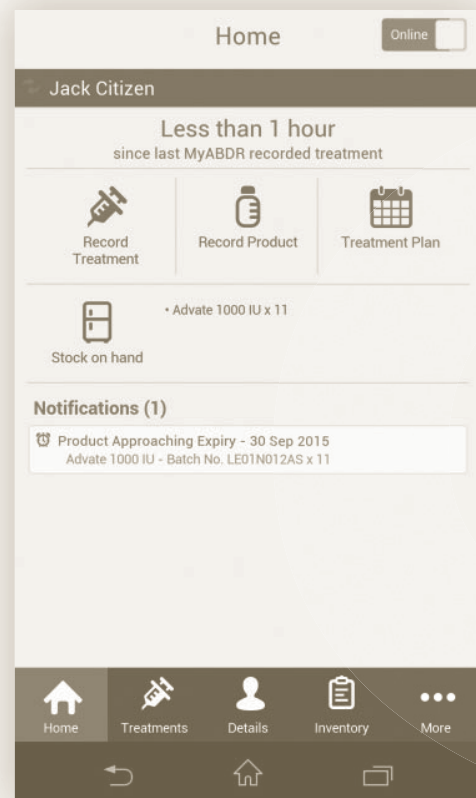
## USER TESTING AND FEEDBACK

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

Available 24 hrs a day, 7 days a week. ☎

# DAMON COURTENAY MEMORIAL ENDOWMENT FUND

## FUNDING ROUND OPEN

The Damon Courtenay Memorial Endowment Fund (DCMEF) was established by Haemophilia Foundation Australia in 1994. This was made possible by donations from the late Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon.

The Fund was set up to provide grants to individuals or patient support organisations for the care, treatment, education and welfare of people affected by haemophilia or related bleeding disorders.

## WHO CAN APPLY?

- Anyone with a bleeding disorder or affected by a bleeding disorder who resides in Australia may apply for a grant
- Patient support organisations in Australia

## WHAT CAN THE GRANTS BE USED FOR?

Applications will be considered for a project, services and/or care, or an activity aimed at improving the physical and emotional wellbeing and independence of recipient/s such as:

- Training, education and coaching
- Career development
- Personal development
- Conferences and workshops
- Medical appliances and equipment to help people live more independently
- Workshops and peer support activities.

## HOW TO APPLY

Submit an application on the official form by 20 May 2016

Application forms and guidelines for the Fund are available:

- On the HFA website [www.haemophilia.org.au](http://www.haemophilia.org.au)
- Or request a copy by email to [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)
- Or telephone HFA on 1800 807 173.

An amount of \$15,000 is available for distribution. Your application will be considered on its merit by a judging panel. There is no limit on the amount that you may apply for, however smaller activities that are likely to be successful or completed with a grant will be favoured. ■

# GO FOR IT GRANTS

The HFA Go For It Grants for 2015-2016 have been finalised!

We are pleased to announce that the panel of judges have awarded three grants rather than two as initially advertised.

Grant recipients:

**Sam Linnenbank** – to fulfil his desire to attend the WFH 2016 World Congress, and to learn more about community representation and leadership. (\$5000)

**Ian Zaro** – for recording equipment to support his passion for comedy and further developing his communication skills for social media (\$2000)

The third grant is provisional and will be announced in due course.

Congratulations to Sam and Ian - and thank you to Pfizer Australia for sponsoring the HFA Go For IT Grants. We will bring you reports and interviews from Sam and Ian in the next issue of *National Haemophilia*. ■



# CONNECTING THROUGH CAMPS

*Claude Damiani*

In 2015, HFNSW was very generous in extending to HFACT members an invitation to its family camp. Several families from Canberra attended what was a fantastic weekend away at the beautifully located NSW Sport and Recreational Centre in Sydney. There was a relaxed atmosphere, in which families felt comfortable meeting and talking to other members of the haemophilia community, and getting to know one another better.

Through these informal connections, a lot of useful information can be exchanged, and this is one of the real benefits of gatherings such as these. The camp program had a good mix of educational sessions (such as latest developments in haemophilia research/trials, infusion demonstrations, and so on) and fun activities that everyone could enjoy (the go-karts and swimming were a particular hit!). One thing that struck me was the number of kids that attended, many with bleeding disorders, but also siblings and relatives. It was great to see the kids

racing around on their bikes and scooters, as all kids love to do, and it really brought home to me the fact that in this day and age, haemophilia certainly does not need to be an impediment to a fulfilling and exciting life. The only part of the weekend that didn't hold up was the weather (it poured most of the time!) but that failed to put a dampener on things.

I would like to extend particular thanks to HFNSW for including HFACT in its camp. It's great to see sister organisations working in partnership; there are so many benefits that can come from widening the community and sharing our respective expertise.

HFACT will be having its family camp in April and has invited members of HFNSW to attend. We hope that many will come along and that we continue to build on this collegiate approach, to the benefit of all members of our respective communities. ■



Having fun at the HFNSW camp

Photos: HFNSW

Hannah Opeskin is Health Promotion Officer, Haemophilia Foundation Australia



# YOUTH UPDATE

*Hannah Opeskin*

## YOUTH LEAD CONNECT

Youth Lead Connect (YLC) is a new Haemophilia Foundation Australia youth leadership and mentoring program designed to build education and life skills for young people with bleeding disorders.

The program has been developed by HFA and is supported by an unrestricted educational grant from CSL Behring. YLC aims to benefit both individuals and the bleeding disorders community through the development of real-world leadership and mentoring skills including relationship and personal development. The program promotes engagement in the community through the development of personal hurdles which must be completed before graduating from the program.

Entry to the program follows a similar process to a job application: interested youth were required to submit an application form to HFA explaining why they wanted to be involved in the program and how they would use the skills learned from the training in their local community. The application also required a reference from their Foundation or Haemophilia Centre. HFA then contacted their referee to determine whether they would be a good fit for the program, had motivation to be involved at a community and national level, and whether they had the support of their Foundation or local Treatment Centre to complete their hurdles. When they were accepted for the program, the participants received a formal acceptance letter from the HFA Executive Director.

The YLC program began in February 2016 with a training weekend in Melbourne. Facilitators included the education team from HFA and Dr Moana Harlen, the Senior Haemophilia Psychologist from the Lady Cilento Children's Hospital in Brisbane, along with expert youth trainers, The Frank Team and Reach. Sessions covered authentic leadership, how to be an effective mentor, boundaries and effective communication.

The weekend took the participants on an extraordinary journey – and it was equally amazing for the facilitators! Questions like which leaders inspire you and how do you want to be a leader made everyone involved in the weekend look more closely at ourselves and what drives us. The session with Reach left everyone thinking about who inspires us every day, whether it be someone we know and see every day or someone we wish to meet someday. It asked participants what motivates them to be part of the program – and their answers were a truly impressive insight into what inspires these youth leaders to be part of the community and help support other young people.

The more personal side to their leadership was explored in the hip-hop song-writing session with Australian rapper Mantra. It led the participants down a path of self-expression, revealing that everyone faced very different struggles daily. The song they wrote together was brilliant and showcased a very dedicated and enthusiastic group of young people committed to being an active part of the community.

As part of the program the youth are required to develop two hurdles to be completed over the next 12 months. A hurdle includes involvement at a local level in a leadership or mentoring capacity as well as writing articles for the Factored In website.

In 2016 the Youth Lead Connect program has 10 participants from across Australia. The training weekend revealed the participants were incredibly dedicated to helping other young people in the community through mentoring and leadership. I can't wait to see the hurdles they come up with. We were really impressed with their ideas for leadership and mentoring. ■



# YOUTH NEWS



The highlight of the weekend for me was definitely the empowering final session with Reach that taught me that leadership doesn't have to always be a big gesture in order to inspire others and is definitely something I will take away into my interactions with local youth in the future.

There is an amazing support network out there for all types of bleeding disorders, male or female, that are always willing to help without judgement or hesitation.

## Lauren



My favourite part of the weekend was writing a rap with Mantra. It was incredibly fun to get creative and put our feelings about bleeder struggles and resilience in words and to put them to music. It was eye opening to discover what everyone found to be the most difficult part of having a bleeding disorder and how they had to overcome these issues. It was heartening to be able to voice these opinions in such a supportive environment.

The biggest thing I learned from this weekend is that the future leaders of this community are an amazing group of people who really understand what we need and want and that we are in good hands.

## Emily

# STORIES FROM THE YOUTH LEAD CONNECT WEEKEND

## Nathan

Reach allowed for deep thought and conversation about leadership, it was a workshop that helped me find some realisation of what it means to be a leader.

One thing I learned from this weekend was that it's okay to share your worry and doubts. People just want what is best for you and by speaking up it will allow for younger people to get the help and answers they need.

My highlight was getting to hang out brainstorming with such like-minded people - that is always brilliant.

One thing I have learned is that there are others out there fighting for what's important to us.



# CALENDAR

## World Haemophilia Day

17 April 2016  
[www.wfh.org/whd](http://www.wfh.org/whd)

## WFH 2016 World Congress

24-28 July 2016 – Orlando, USA  
World Federation of Hemophilia  
[www.wfh.org/congress](http://www.wfh.org/congress)

## Haemophilia Awareness Week

9-15 October 2016  
Tel 03 9885 7800  
Fax 03 9885 1800  
Email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
[www.haemophilia.org.au](http://www.haemophilia.org.au)

## CORPORATE SUPPORTERS AND DONORS

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

- represent and understand the needs of the community
- provide education and peer support activities to increase independence and the quality of lives of people with bleeding disorders, and their families
- encourage clinical excellence in haemophilia care, and promote research.



CSL Behring



# Have you **changed** your **email** address lately?



If you have changed your email address in the last year, please let us know so that we can update our databases!

Email your **name** and **new email address** to  
[hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au).

Or phone **1800 807 173**.

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