Haemophilia Foundation Victoria Inc — *Achieving the extraordinary together*

THE MISSING FACTOR

LISTEN TO YOUR HEART — Neil Boal

PAIN really is in the mind, *but not in the way you think...*

BLOOD BROTHERS CAMP 2015

20th-22nd November 2015

Don't miss out on this free camp... there's still time to book!

OVERCOMING ROADBLOCKS

A youth persective — Scott McDonnell

contents

cover stories

our features

hfv team

Haemophilia Foundation Victoria Inc

ABN: 67 922 470 900

13 Keith Street, Hampton East, VIC 3188

P. (03) 9555 7595 F. (03) 9555 7375

E. info@hfv.org.au

www.hfv.org.au

Andrea McColl | Executive Assistant

andrea@hfv.org.au

Julia Broadbent | Communications Coordinator

julia@hfv.org.au

DIARY DATES

Blood Brothers Camp —
Fri 20th to Sun 22nd Nov

HFV Remembrance Service —
Sun 29th November at 10am

Family Christmas Picnic —
Sun 29th November 10.30am onwards

HFV AGM —
Sun 29th November 12pm

HFV extended office closure —
Tues 22nd Dec 2015 until
Mon 18th Jan 2016
(Please leave a phone message or email info@hfv.org.au as staff will continue to monitor correspondence during the office closure).

RCH Teachers Seminar —
Fri 19th Feb

HFV Family Camp 2016 —
Fri 1st to Sun 3rd April

Grandparent's & Friend's Lunch
Sun April 17th

A word from *our* president, Leonie Demos

Committee of Management

President
Leonie Demos

Vice President
Sharron Inglis

Treasurer
Zev Fishman

Executive Member
Ann Roberts

General Committee
Jodie Caris
Karen Donaldson
Carol Ebert
Donna Field
Ben Inglis
Fiona McDonnell

Another busy period at HFV as we all look to the holiday season for a break on the horizon. The weather is warmer and all at committee have a spring in our step to continue to work hard to benefit our community.

The National Conference 'Facing the Future Together' on the Gold Coast was a massive success. Congratulations to our peak body HFA in organising a fantastic conference with a high calibre of speakers and facilitating many productive sessions for all who attended including medical professionals and members of our community as consumers. An amazing achievement indeed. Hopefully over the next few issues there will be many reports to share the information to our members as well as encouraging you to check websites to read presentations and learn from the specialised health providers that we are so fortunate to have working together to look after our community.

Closer to home the committee has been busy finalising changes to our Constitution and working hard on the Strategic Plan to shape the work at HFV in coming years. These will be presented to you, our members at the Christmas gathering which is also our Annual General Meeting. We would love to see as many members attend as possible. It will be a very special event to celebrate a hard year of work at HFV by our amazing staff and peer support leaders as well as a chance to have some fun in the beautiful Royal Botanic Gardens we are blessed with in our city of Melbourne.

As with all AGM's it is the time to elect the new Committee and to call for new members to become involved with HFV. If you have an interest in putting your hand up or wish to share one of your skills we would love to hear from you. HFV are continuing to build diversity into how we deliver programs because we know we support a very diverse and unique community. It is your uniqueness that makes HFV, so please consider offering some time to support the work we are doing.

A bumper issue of the newsletter to enjoy as a reflection of a bumper time at HFV. Look forward to seeing some of you at the AGM or hearing from you about your ideas on strengthening HFV as we build on the theme of the conference to 'face the future together'.

The Fuller's Journey…

We first met Leo and Beverley Fuller at a regional visit to Horsham. After being HFV members for many years they were pleased to have an opportunity to attend an event in their region. During the lunch, it became apparent that they had a very powerful story to share. It very much touched us and reminded us of our not so distant history and the difficulties we have faced as a community. I only have to revisit our HFV newsletters from the 90's to know there are many families who had a similar journey.

I recently spent an afternoon with Leo and Beverley who kindly agreed to share their story. Without doubt it was painful and difficult to discuss, nonetheless both Beverley and Leo saw value, for our community, in sharing their story. I sincerely thank them for their contribution.

Leo is a third generation farmer whose family selected and cleared the original 1000 acre property at Yaapeet over 110 years ago. Bev grew up in Lilydale but moved to Yaapeet when she married Leo. They had three children, Karen, Jon and Rohan.

Rohan, the youngest, came into the world in July 1972. When he was born he had a massive haematoma behind one eye. The doctor was not too concerned as it could have been caused by the pressure of birth. When Rohan was eight days old and still in hospital, he was due to undergo a circumcision, however he still had the haematoma around his eye which had started to concern the doctor. It was at this point that Rohan and Beverley were sent to the Wimmera Base Hospital in Horsham for further investigation by a visiting eye specialist. From there they were both flown to the Royal Children's Hospital. Rohan was less than two weeks old when it was considered that he may have haemophilia. A definite diagnosis was made when he was three months old and this was the start of their journey.

Dr Colebatch and Professor Ekert were the first haematologists Beverley and Leo came in contact with. Leo still remembers asking Professor Ekert what having haemophilia actually meant. He had known of a 'bleeder' in the local area with obvious mobility issues but that was all Leo really knew about haemophilia. It was after this both Bev and Leo's factor levels were tested. Only after several tests was it confirmed that Bev was a carrier and to the surprise of the doctors Leo also had von Willebrand Disease. This meant Rohan had a mix of both conditions. This combination of haemophilia and vWD was very unusual and the Fuller's proved to be an interesting case study for Professor Ekert and his student doctors. Leo's late diagnosis of vWD made sense to him as he had had a number of bleeding issues throughout his life such as bleeds into his thighs during footy games, constant nose bleeds and a tooth extraction that bled for days but none that had sent him to hospital. In later life Leo has had more issues and finds it still very difficult to get doctors who are not in this field to understand about vWD. Leo is a firm believer in the importance of advocating for yourself, explaining your condition and making sure the doctors understand before any procedure.

At eight months of age Rohan began to walk but had many falls and seemed to retain a constant haematoma on his forehead but luckily a solution came to mind – Professor Ekert arranged for a bicycle helmet to be made for him, which solved the problem! His first major bleed was when he was about a year and a half old. He couldn't really talk but managed to get the word SORE out and held his knee. His parents took him to the local doctor who offered bandages to pressurise the knee. Leo then called Professor Ekert who told them to come straight to the Royal Children's Hospital, a 450km drive through the night. This was their first introduction into what joint bleeds really meant.

It was ankle bleeds that were Rohan's biggest issue though. At seven years of age Rohan managed to fall off a swing at school and break his leg that was already in plaster to immobilise his ankle joint. It was a stressful time. He had a mouth bleed from apple peel getting caught in his gums, followed by a severe allergic reaction to the cryoprecipitate used to treat this bleed. From that point on he was treated with Factor VIII.

Rohan initially received his treatment from his local GP at Hopetoun, about 30kms away, but being the only

doctor in the small town meant you might not be able to find the doctor when the treatment was needed, very often in the evening or at the weekend – he may have been in meetings or even out socialising! So Bev was trained to perform the treatments on Rohan who was an exceptionally good patient and Leo was happy to take a step back. But it wasn't long before Rohan, who was fiercely independent, decided he would manage his own treatments. The idea of his mum attending school camp to administer treatment didn't sit well for Rohan and it was important to Rohan to have a sense of control over managing his condition and his treatment. And luckily, Rohan had a strong sense when he needed treatment even before a bleed was apparent.

The Fullers lived in a small community. There were only 15 children enrolled in their local school so it was important for the whole community to know about haemophilia and understand the condition to some extent. Both Rohan's primary and secondary school were very supportive.

Rohan enjoyed sport. He played junior tennis for the Yaapeet Club when he could, also ran the boundary for the junior football team. There were many activities Rohan couldn't be part of during his teenage years. He was very passionate about football (and football is a big thing in the country) but he found ways to be involved whether it be running the boundary, time keeper or running the social committee, and he was very much integrated into the footy club – which he craved.

Rohan wasn't a big fan of school. He was very much an outdoors person. He was always out and about enjoying nature, wandering through the scrub and watching the mallee hens attend to their mounds. Most evenings Bev would shout from the back door for Rohan to come home for his dinner and the pet cockatoo would join in, both shouting "Rohan"! He loved shooting, which was a great outlet for him. He and his cousin Gene spent much quality time together travelling to trap shooting events. Rohan was interested in historical pieces and he'd spend months and months digging for artefacts and treasures.

By this stage the haemophilia community had been well aware of the impact of HIV. Rohan and his parents knew there had been a risk of exposure to the HIV virus, however it was Rohan's choice at that time not to know his status. When HIV was first publicised a number of parents, including Leo and Bev, presented at the RCH offering to be direct blood donors. Unfortunately this was not possible as they discovered extracting the factor for blood is a very complicated process.

Rohan had been unwell and diagnosed with glandular fever at about 11 years of age. He developed very swollen glands under his arms. Both Rohan and his parents had a strong feeling that his symptoms were not due to glandular fever. Unfortunately their gut feeling proved correct. At age 14 it was confirmed that Rohan had HIV. Rohan's wish was for nobody to know about his HIV status including his siblings and extended family, and so his parents, as difficult as it was honoured his wish and kept it a secret, understanding how terribly important it was for Rohan to let his life remain as normal as possible. The wave of haemophilia related HIV publicity had died down somewhat so nobody in the community asked questions. Rohan completed year 10 and reluctantly did year 11 saying 'That was for you mum' on completion – a very touching gesture for Bev.

After school Rohan did a farm apprenticeship in Swan Hill and also worked on the family farm. It was a really valuable time for Rohan as he built social connections and networks. Rohan was born to be a farmer – it was in his blood. He was always on the farm with his father – his father needed him, he was quite sure of that! After learning of the Young Farmers movement in Swan Hill he took it upon himself to organise a branch of the

Young Farmers Organization in Yaapeet – a powerful network for the young farmers in the community.

At his 21st birthday his father Leo made a speech and talked about the party as a celebration of Rohan's life. As Leo said with a heavy heart "at the time only a couple of people in the room knew the significance of my words – but for us it truly was a celebration of his life and a significant milestone".

By this time Rohan's health started to deteriorate. His ankles were extremely arthritic and very painful. He decided to have an ankle fusion even though the doctors at the Alfred Hospital advised him against it. They supported his decision however. The operation was successful but his health declined further. Rohan was battling to keep his HIV status a secret as he was losing significant weight. It was at this point Rohan decided it was time for people to know. Rohan contacted friends personally. Leo and Bev spoke to family and the wider community. It was an incredibly difficult and devastating time for them all. The community were extremely supportive. It was harvest time and farmers came from many miles with trucks and headers to a working bee to complete the harvest at the Fullers. They received constant food parcels and were overwhelmed by the support offered to them.

Rohan's doctors put him on a cocktail of drugs, however it was too late to reverse the damage already caused by the virus. Rohan's stomach lining was ruined which meant he needed to be peg fed. His health continued to deteriorate and it was at this time Rohan was told by his doctors that if they did nothing he would fade away after 2 weeks or he could be intravenously fed and hope for longer. Supported by Leo and Bev, Rohan opted for the second option. Rohan lasted for a further five months. He was 23 when he died. The Alfred staff gave Bev and Leo an envelope containing information on grieving and loss, as requested by Rohan before he passed.

For Rohan's parents, Leo and Bev, at that time they felt very angry at what their son had had to endure and that they had lost their son – a brother, a cousin and a friend. They were angry at the cause and how it had happened. But they understood that as parents you have to make decisions on the best interests of your child and Rohan like all boys with haemophilia had to have his haemophilia treated regardless of the pending risk at that time.

February of 2016 will mark the 20 year anniversary of Rohan's death. Although for Leo and Beverley and their family it has been a difficult two decades with Rohan never far from their thoughts they have also had much happiness with the arrival of grandchildren and the continued support of their community. Sometimes it is bittersweet, "I see Rohan in my grandson Joad, they are very similar in personality and character and I have to stop myself from calling him Rohan", said Leo. As for the grieving process Leo and Bev both said "You can't be angry for the rest of your life – you just have to let that go. As for grief, there is no formula. For the first year we'd always talked with tears. It doesn't get easier but you just get better at overcoming the high sense of emotion. We went to the Alfred and spoke to the social workers there. Their advice was to let it out and talk about it and that's what we did – talked about it and we still do."

Julia Broadbent

HFV REMEMBRANCE SERVICE

Sunday 29th November at 10am

Details on page 22

Ann Roberts
HFA Life Governorship Award Recipient

Our HFV conference delegates were delighted to see the work of Ann Roberts – an exceptional member of our community, long time committee member and strong advocate for people with bleeding disorders recognised at the 2015 Gold Coast Conference.

Ann received the HFA Life Governorship Award. Life Governorship is the highest recognition in the HFA Awards Program and is only given in exceptional circumstances. It may be given to an individual for his or her exceptional leadership and commitment to the objectives of HFA over many years and a current or past member of the HFA Council who has earned special recognition for his or her continuing efforts to seek a goal/s to benefit the bleeding disorders community.

The HFA Life Governorship has only been given to 12 others during the history of HFA. The last was to Rob Christie, HFA President in 2003.

It was a proud moment for us – the HFV contingent, to have our former president recognised and honoured in such a way.

Congratulations Ann. A truly deserving recipient!

Ann Roberts (centre) with Jenny Ross OA and HFA President Gavin Finklestein

Ann with her husband, Danny

Ann, Jenny Ross OA and Zev Fishman

Ann with Jen Jeski

HAEMOPHILIA AWARENESS WEEK 2015

HFV was delighted to have a number of member led activities around Haemophilia Awareness Week and the theme 'Red Cake Day'.

Donna Field and her family Grant, Emma and Adam have held an annual 'Paint the Town Red' awareness campaign in their home town of Neerim South for a number of years now. This has been supported by many people in their community including the local butcher, Tip Top bakery, Donna's workplace – The Bendigo Community Bank and of course the people of Neerim South.

We are very lucky and proud to have Donna on our committee. She had a vision of something achievable and was very happy to step up and get involved.

In Donna's own words 'I just wanted to give back to the bleeding disorders community in a small way and thanks to the support of my local community it has blossomed into something much bigger. It's easy to start small - with a sausage sizzle in your back yard or some red cakes in your local shopping strip and it's a great way to meet the locals and increasing awareness of something close to all our hearts.'

Donna's enthusiasm, personality and initiative has led to a much bigger campaign this year involving The Bendigo Community Bank. This small community based initiative has now grown into a national campaign supported across the country by the Bendigo Community Bank. This is a huge step up in increasing awareness of bleeding disorders and of potentially raising funds to assist people in our community.

We also had the Grech family from Geelong participate in a Red Cake Day at their school Hamlyn Banks Primary. The children were allowed to wear red to school and bring a red cake to school which they could decorate with red icing at the 'icing station'. It was a great success with over $400 raised! Harrison even made it into Geelong Advertiser! A great day with a really positive awareness message for their local and wider community.

Paramedics and Ambulance Community Officers support Haemophilia Awareness Week

This article featured on the Ambulance Victoria website during Haemophilia Awareness Week. There were also a number of articles featured in local Leader magazines throughout Victoria. We are delighted to have our members and their families help raise awareness of bleeding disorders in such open and positive ways.

Ambulance Victoria Paramedics and Ambulance Community Officers (ACOs) are supporting Haemophilia Awareness Week, which runs from October 11 to 17.

The cause is close to the heart of Graduate Ambulance Paramedic Tim Demos, Geelong Mobile Intensive Care Ambulance (MICA) paramedic Matt Donaldson and Neerim South ACO Donna Field.

Haemophilia is an inherited bleeding disorder where a person's blood doesn't clot properly.

It is caused when blood does not have enough clotting factor, a protein in blood that controls bleeding.

Graduate Ambulance Paramedic Tim Demos, who is based in Dandenong and lives in Melbourne's outer east, said he was diagnosed with haemophilia as a young child after he kept getting covered in bruises. He has no family history of the disorder.

Tim said having haemophilia even influenced his career path.

`Spending a lot of time in hospital as a kid made me want to do something medical-related. From about 10 onwards I was pretty keen to be a paramedic,' Tim said.

Haemophilia, von Willebrand Disorder and other related inherited bleeding disorders affect about 5800 Australians, most of who are male. Many manage the disorder themselves.

`I'll laugh the day I do meet a patient that does have haemophilia. It's pretty rare so I'm not holding my breath,' Tim said.

`When you've been on the other side of it, of being helpless to your own body it's a frustrating feeling. I guess I can definitely empathise with patients more generally who have no control over their own health and how scary that can be.'

Neerim South ACO Donna Field's son Adam was diagnosed with haemophilia at just seven days old. Paramedics transferred Adam, now 11 years old, from West Gippsland Hospital to the Royal Children's Hospital where he was diagnosed and had an operation to stop the bleeding on his brain.

Donna will run her annual Paint the Town Red event in Neerim South as part of Haemophilia Awareness Week. `We put balloons up, streamers up in the town, posters in the shops and get the local schools involved,' Donna said.

`On Saturday 17 October we will run a stall in the main street selling hundreds of red cupcakes and a BBQ. We've also got a raffle with prizes from local businesses.

`It's a way of giving back and saying thanks to all the people that have supported us as well as keeping the awareness out there in the community.'

Geelong MICA paramedic Matt Donaldson's eight-year-old son Will has haemophilia.

Matt will host a Red Cake Day at his ambulance branch on Sunday 11 October to raise money and awareness.

`Because it's a pretty rare disease it's a chance to increase awareness among paramedics about haemophilia because it's not something we go to every day,'' Matt said.

`We've been managing Will's condition from home since he was three months old. He lives a normal life. He surfs. He plays soccer. He runs around the school yard.

`At work, I go to children who have been involved in backyard accidents, school yard accidents, motor vehicle accidents, different kinds of trauma, and sometimes you catch yourself thinking, `This could be my child' and I wonder how we would cope with if it was my child.

`The impacts of major trauma can be compounded for someone with haemophilia because they have a greater tendency to bleed into the skull.'

Haemophilia Awareness Week and Red Cake Day will be held from 11 to 17 October 2015.

More information about Haemophilia and Haemophilia Awareness Week can be found at https://www.haemophilia.org.au/ .

Listen to your heart...Neil Boal

On Thursday 10.50am July 30th, age 52, I had a dose of Aspirin. Not such a big deal for most people but for those of us with a haemophilia connection it's something that goes against everything we've ever been told, and now I'm on it for life!

The story begins with my new ability to actually start walking for exercise, something I haven't been able to do for years, thanks to a couple of very successful ankle fusions (more on that another time).

At the start of the year Julie and I began a walking regime. I was really keen to at least try to improve my health, both in mind and body, if the ankle fusions enabled me to. At about 4 months post second surgery I managed a very slow but very deliberately stepped one kilometre.

We did this every second day over summer and autumn gradually increasing distance and speed. With the aid of phone apps we were recording 3 to 4 k's at about 11 minutes per kilometre. I was feeling pretty happy about it all and even hit 5k's a couple of times.

When winter hit we thought the weather might really challenge our resolve but we still got out about every 3rd day. Unbeknownst to us, our resolve was about to be tested by a total stranger.

About 4 weeks before the above mentioned date, about 100 metres into our normal brisk walk (well, brisk for me) I felt a tiny, dull ache right smack bang in the middle of my chest. So I guess you now know where this is going.

I don't want to get bogged down in what was happening around me at the time but the short story is I had some medication changes and side effects so thought this could be the possible cause of the ache.

One new drug I had just started did state that in some very rare cases chest pain was indicated. So I stopped the drug and waited a week for it to clear my body. I also tried some anti-indigestion chews that made no difference. We still walked but had to drop the pace right back to where there was no pain at all.

I wasn't overly concerned as there were no pains in my left arm, no tightness in the chest, no shortness of breath or any pain when resting. When I thought I'd ruled out the drug effect that's when I went to the GP.

I guess I should mention that I live just over 100k's from the Alfred so that's why I didn't go straight there. The GP diagnosed me with potential stable angina, a heart problem!

Okay, now I was starting to get concerned, but due to some unfortunate timing and me trying to get some tests done locally, my admission to the Alfred was delayed another week or so.

Not being happy with how slow things were taking and I was just feeling a tiny bit worse, Julie and I decided to ring the RSHTC and were advised to drive straight to the Alfred emergency which we duly did!

In emergency I had an ECG which was normal but blood test showed further investigations were warranted and I was admitted up to the heart ward on the 3rd floor.

My first test was a stress test which was a 6 minute exercise bike test of increasing resistance. I got to the 4th level and failed miserably, not due to any chest pain but my legs were burning and I couldn't go a second longer! My Tour de Alfred was over!

The only option left was to have a chemically induced stress test. This turned out to be the most unpleasant part of my week long stay.

This test also lasted 6 minutes as a chemical was slowly pumped through to my heart and man, did this stress the old ticker out? I went all hot and clammy; my heart felt like it was going to jump out of my chest and I felt more than a little panicky!

However the doctor and nurse had informed me before hand and were very reassuring. When the injection ceased all of the symptoms stopped within 30 seconds and that was a big relief.

Directly after that I had front and rear chest x-rays, with some contrasts, ending the tests needed.

The next day the Cardiac surgeon and his team informed me that I had to have an angiogram for further investigation which didn't really concern me.

I'm an avid watcher of real life medical TV shows so I'm well aware of heart procedures as well as having some family experience. Naturally I was hoping for best case scenario and if there was some sort of blockage then a stent could be used which is a much less invasive event.

However the surgeon said they don't like using the stent method on people with haemophilia so it was more likely to be open heart surgery! My heart sunk with that news as I really didn't want to go through another bout of painful recovery less than 12 months after my last ankle surgery.

Thankfully, when the haemophilia team came they said a stent has been used easily and successfully in our case many times. What a massive relief!

So on that Thursday mentioned above, I was scheduled to have the angiogram. I had my dose of aspirin, as well as my factor, got prepped by way of having a wrist and groin shaved and headed to theatre.

My procedure was done via my left wrist. They prefer to do this because any bleeding that may occur can be easier to control than from your groin.

After a dose of local anaesthetic into the wrist, a small cut is made and a catheter is inserted into the artery and pushed up towards the heart.

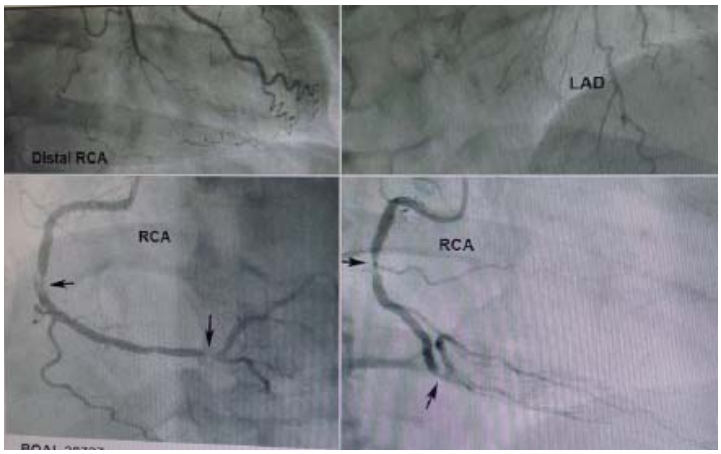
While all this is going on there is an x-ray machine hovering above my chest taking constant images which I watched on the giant screens that the surgeons are using to assist in the procedure.

Contrasts were injected which displayed my arteries and veins around my heart like a river system with lots of little creeks running off in hundreds of different directions. At the same time as being amazed at the pictures I then saw the reason I was in theatre for, 2 narrow spots in my right artery! They mentioned it was an 80% blockage which sounds a lot but I really only had a tiny bit of pain. Then a deflated balloon was guided to the first position and expanded to unblock the problem and then a stent placed in situ to keep the artery open. Naturally they had to repeat this for the second blockage.

I felt a little discomfort in my chest whilst they were doing this but overall it really was the most painless procedure I've ever had (well, so far)!

To finish off they even put a camera up my arm and look at the inside of my artery and check the final positions of the 2 stents! Amazing! Lastly to stop the bleeding a clear plastic wrist band was put over the cut and then filled with air to apply pressure, not even one stitch was needed.

Then I was wheeled back to my room and the pressure was released gradually after a couple of hours and the bleeding was stopped. I was then allowed to go home the next day.



I had to have a month of prophylaxis due to an extra blood thinner I was on (to avoid the stents from clotting) and now I'm back to normal and walking regularly. I've just about completed a 6 week stint of rehab which was basically an exercise program and some healthy lifestyle education.

Although the worry of the heart pain was huge, I'm just so happy, and amazed, at how stress free the surgery turned out to be.

I hope nobody has to experience this but it's kind of helpful to know that these types of surgeries can be performed on our community with great results.

Neil Boal

Pain really is in the mind, *but not in the way you think*

Professor Lorimer Moseley presented a session at the 17th Australian & New Zealand Conference on haemophilia & related bleeding disorders. It was a fascinating insight into pain and how our brains perceive pain. For more information please go to www.bodyinmind.org

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.

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

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 an 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.

Lorimer Moseley

Professor of Clinical Neurosciences and Chair in Physiotherapy, University of South Australia This article was originally published on www.theconversation.com There are also some fascinating videos on www.bodyinmind.org

WOMENS WISDOM

vWD Women bleed too

There are so many issues impacting on women's health HFV are looking at expanding our knowledge and the possible support that can be offered. HFV would encourage women to come forward to offer support to other women and expand knowledge across our community.

At the recent conference a number of HFV members attended a very interesting session on von Willebrand Disease. There were a number of speakers. including a woman with vWD, a mother of a girl with vWD, a diagnostic doctor and a specialist. Here are just some points to start the conversation.

Bobby is a science communicator who creates film and multimedia for the Australian Government. Despite numerous chronic conditions, she thrives on sunlight, emerging technology, fine art and finding humour in the darkest of places.

Diagnosed at birth with vWD, Bobby had a life characterized by love, laughter and cutting-edge science facts. Everything was going well - this is, until she tried to have children, a wisdom tooth extraction and a PHD all at the same time.

Bobby shared her experiences of living with vWD in a very open and frank manner. Bobby discussed how her condition often made her feel isolated growing up and the importance of owning information and the need to be your own advocate. The final message from Bobby was what she has taken away from her experiences and what is most important - love, care and community.

Sally is the mother an 11 year old girl with type 3 vWD and they live in rural New South Wales. There were issues with misdiagnosis early on and Sally's daughter had low iron level due to persistent nose and mouth bleeds - often requiring hospitalisation. In important lesson learned by the family during these episodes was to bypass the emergency department and seek direct contact with the specialist.

Sally noted that living regionally meant they were a long way from the hospital and they had encountered issues with the local GP service. And living in a small community meant everybody knows - which is sometimes good and sometimes bad. It also meant they had limited contact with other people with vWD and had only met one other family with type 3 vWD. This is why their state Foundation Family Camps were so important to their family - to have that opportunity to connect with others in the same situation.

Dr Ritan Prasad, a haematologist at the Royal Hospital Hobart spoke about diagnosis and treatment. From a lay persons perspective it was a fascinating insight into the highly complex process of diagnosis - something many of us would have assumed would be straight forward.

Dr Susan Russell, a paediatric haematologist oncologist and director of the Haemophilia Treatment Centre at the Sydney Children's Hospital spoke in depth on the treatment and management of people with vWD.

For more information on vWD and other bleeding issues for women please go to the HFA website.

www.haemophilia.org.au/bleedingdisorders/women-with-bleeding-disorders

Here is an opportunity through the Bendigo Bank for assistance if there are any members struggling with the costs of University...

www.bendigobank.com.au/public/community/scholarships

Looking to go to university? Need help with expenses? If you're a first time university student you're looking in the right place. Bendigo and Adelaide Bank offers Australia's leading scholarship program. From agriculture based scholarships, to those connected to one of our many Community Bank® branches, we have something to help you reach your university dreams.

Applications for 2016 places are open from 1 December 2015 and close at midnight (AEDT) on 25 January 2016.

YOUTH YAK

Overcoming Roadblocks

There's a certain point in the transition between kid and teen where haemophilia really starts to suck.

The pressure of school work begins to take hold, you may be learning to vein access or you're tired of the same routine. Whatever it is, one day you'll catch yourself hating haemophilia and asking "why me".

My breaking point was entering high school when my port failed and I had to start learning to access myself, after a few successes I hit my first roadblock; missing a vein, this relatively minor mistake sends an entire shock wave through your system and slowly tears apart your self esteem, suddenly I was up at all hours of the night trying to access a vein with my mother by my side, my arm a complete mess and tears streaming down either mine or my mothers face, usually both. These nights usually included me childishly screaming my hate for haemophilia and eventually giving in and going to emergency or one of our doctor/nurse friends to access me.

There was an immense amount of vulnerability that would suddenly overcome me, I wasn't as confident as I once was and truly felt alone with my disorder. This was all in less than a year but it felt so much longer. So what changed? The Haemophilia Foundation Victoria was always there to help and provided me with the support I needed, but what really changed everything was the first haemophilia youth camp provided by Purple Soup. I had been to other haemophilia camps before but this was the first time it was just guys with haemophilia. Meeting and becoming close with these guys changed everything, they were these healthy, active, charismatic men who had been through the same ordeals as me and had come out stronger because of it, by the end of the camp we had adopted the collective name "blood brothers" and I knew I had true friends I could always rely on for my haemophilia and I knew I'd be alright.

Following the camp, my confidence had grown immensely and I was able to access again, I wasn't afraid of errors (there were plenty) because I knew it was just a hiccup. Half a decade later I see the next generation entering this nightmarish phase of their life and there are things that I wish I'd known sooner. Don't be afraid to ask for support. It's very easy to hate haemophilia and everything associated with it, such as family camps and hospital visits, but these are the best times to come to terms with your disorder, and gain vital information and assistance. I can't count the number of times I've seen someone have a breakthrough during camp, consulting someone older with experience makes a significant difference.

Don't think that you're defined by your disorder, but wear it as a badge of pride, not because you have haemophilia but because you have the strength and resilience to handle it. Haemophilia works as a crucible; it applies pressure on you and you come out stronger because of it. I can say with certainty that some of the purest people I know have haemophilia.

Scott McDonnell

PBAC decision on new Hep C drugs
Update from HFA

In August 2015 the Pharmaceutical Benefits Advisory Committee (PBAC) recommended adding Viekira PAK® to the Pharmaceutical Benefits Scheme (PBS) for the treatment of chronic hepatitis C genotype 1. HFA welcomes this decision.

GREAT NEED FOR EFFECTIVE NEW TREATMENTS

The PBAC evaluated the treatment thoroughly and stated that all the approved new treatments for hepatitis C are very effective - both Viekira PAK and the other hepatitis C treatments approved in March 2015. They recognised that these all-oral interferon-free hepatitis C treatments are greatly needed as a treatment option on the PBS.

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

ACCESS DELAYS

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

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

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

The next step in the process is for the Australian government to consider the PBAC recommendations and make decisions about funding. We hope the cost of these drugs can be negotiated successfully with the pharmaceutical companies without delay.

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

AND IF YOU HAVE HEP C?

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

• Make sure you have your liver health checked regularly
• If you don’t know where to start, ask your Haemophilia Centre for a referral
• Stay in touch with your hepatitis clinic about what’s new
• Don’t forget to go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable at the moment
• And for comprehensive care, let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

HFV Annual General Meeting

Will be held at on
29th November 2015 at 12pm
at the Ian Potter Garden
Royal Botanic Gardens Melbourne

(during the HFV Family Christmas Picnic)

Ten years of the Haemophilia Teachers' Seminar

Julia Ekert, Chris Barnes, Nicola Hamilton, Janine Furmedge
The Royal Children's Hospital, Melbourne

Background and aim

The Royal Children's Hospital, Melbourne has conducted an annual Haemophilia Teachers' Seminar since 2006 with the support of Haemophilia Foundation Victoria. The goal of the seminar was to address a perceived lack of information available for schools to assist families dealing with the stress of a child with haemophilia starting pre-school or school. In addition there remains significant uncertainty amongst educators regarding haemophilia management and the expectations of meeting the needs of a child with a potentially life-threatening bleeding disorder.

Evaluation method

Formal evaluation has occurred over a ten-year period via written questionnaire completed at the end of each seminar. A combination of question types was used, including:

- A five-point rating scale to evaluate the overall value of the seminar and whether teacher expectations were met.
- Focused and open-ended qualitative questions to explore what teachers considered to be key messages and to invite positive and negative feedback to guide future seminar content.

Seminar structure

The half-day program includes a formal series of lectures with three health professionals presenting for 30 minutes on their specialty.

Content includes:

- Medical consultant: history, pathophysiology, psychosocial impact on children and families, treatment.
- Nurse: home treatment, identifying bleeding episodes at school, first aid and action plans, school camp.
- Physiotherapist: maintaining healthy joints and muscles, safe participation in activities and sport, rehabilitation after bleeds.

For the final session, boys with haemophilia (primary and secondary school students) are invited to talk about their experience of having haemophilia in the school environment. Teachers have the opportunity to ask questions of the boys and their parents.

Results

Feedback from participants has been overwhelmingly positive. Ninety-eight percent of respondents felt their expectations had been well met (rank 4–5) and that the seminar was very valuable (rank 4–5).

Themes identified from comments include reduced teacher anxiety, confidence to manage injury/bleeds, the importance of normalisation and an appreciation of parental anxiety.

Feedback based modifications

Conducting the seminar in the third or fourth week of term 1 worked well for teachers, but advertising the seminar at the beginning of the busy school year was problematic. Flyers are now sent out early in term 4 ready for the following year. Teachers enjoyed hearing from a range of speakers covering different aspects, however feedback from 2006 highlighted the need to avoid repetition and presentations were modified accordingly.

The majority of teachers reported that watching video footage of children receiving intravenous treatment greatly assisted their understanding of what children dealt with at home, however a small number of respondents described needle anxiety and feeling faint. We now take care to place a 'needle alert' prior to this section and alert participants in advance. The opportunity to hear from the boys and their parents has proved to be the most popular part of the seminar; *'the children's voice was so beneficial'*. This is now scheduled as the finale to allow all questions to be addressed and to finish with a fun and interactive session.

Video conferencing has been used to connect with a small number of distant rural schools over the last three years and feedback using this technology has also been positive.

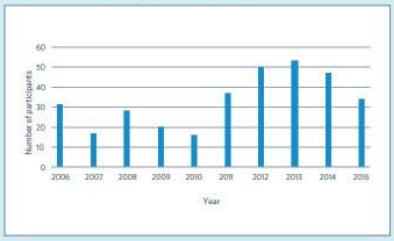
Conclusion

Modification of the haemophilia teachers' seminar based on feedback has resulted in a program designed to meet the needs of educators in providing information about children with bleeding disorders. The success of the seminar highlights the potential for this type of education format to be incorporated into a comprehensive haemophilia treatment centre. This model may also be appropriate for other medical conditions.

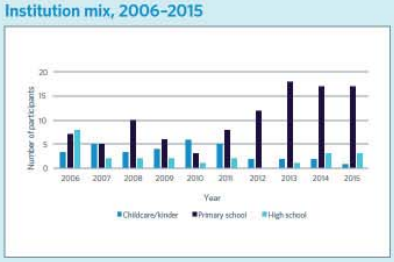
Participant feedback

What was the single most important message at today's seminar?
That a child with haemophilia will not bleed to death if they fall over in the playground. I feel much more relaxed — thank you.
There is no need to panic if the child is hurt.
A greater understanding of what the parents go through.
Allow the child to integrate totally with the school environment. Do not separate or treat differently.
Any other comments?
I was really nervous about having a child with haemophilia in my class – today has put me at ease, thank you.
I feel better prepared to look after and enjoy the company of the child in my care.
I found talking with the kids to be invaluable. It put a different perspective on the condition and how to treat the individual.
Thank you for this Professional Development (PD). If each child with a disability/disorder were to have such PDs, teaching them would be so much easier.

Number of participants, 2006–2015



Institution mix, 2006–2015



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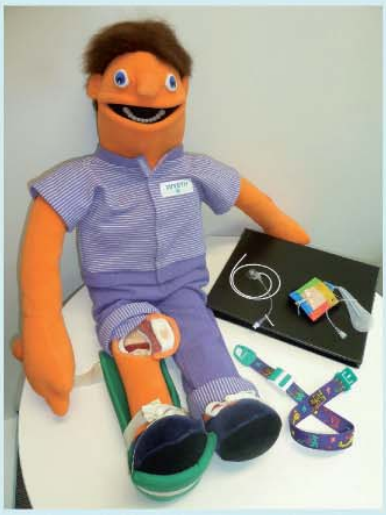


Bob the haemophilia doll and other teaching materials are made available during the seminar

Student presenters at the Teachers' Seminar 2013
Clockwise from top left: Director RCH Haemophilia Centre Dr Chris Barnes, Haemophilia Youth Mentor Tim Demos, RCH patients Xavier, Josh and Nathan.

Acknowledgements

The RCH Haemophilia Treatment Centre gratefully acknowledges the support of Haemophilia Foundation Victoria in conducting this seminar.

Developing a 21st century Electronic Health Record System

Minister for Health Sussan Ley has announced the Committee that will oversee the rebooted personalised My Health Record system for patients and doctors.

Minister for Health Sussan Ley today announced the Committee that will oversee the rebooted personalised My Health Record system for patients and doctors as part of a $485 million package to deliver Australians an electronic medical record system.

Ms Ley announced the appointment of Ms Robyn Kruk AM as the independent chair of the eHealth Implementation Taskforce Steering Committee responsible for the establishment of the Australian Commission for eHealth.

"A functioning national electronic medical records system is essential to ensure doctors, nurses, pharmacists and other healthcare providers across the country had instant access to the information needed to treat patients safely and efficiently without having to gamble on unknowns in their medical history," Ms Ley said.

"As patients, we've all been in the situations where we've had to attend another GP surgery because we were out-of-town or couldn't get an appointment with our regular doctor. It can be a time consuming and often frustrating experience for patients and doctors alike."

In the 2015-16 Budget, the Coalition Government announced $485 million for the redevelopment of the My Health Record system to strengthen and transform national digital health governance through an Australian Commission for eHealth.

Ms Ley said the Implementation Taskforce Steering Committee brings together clinicians, public and private healthcare service providers, consumers, health informatics and analytics specialists, technology innovators and people experienced in delivery of digital health services.

Ms Kruk will be assisted by the skills and expertise of Dr Steve Hambleton, Dr Ewen McPhee, Dr Chris Pearce, Mr Richard Royle, Dr Eileen Doyle, Ms Jan Donovan, Mr Peter Cooper, Mr Mike Walsh, Mr Stephen Moo and Mr Paul Madden.

"In this modern world where technology makes information sharing boundless, it is essential Australia has a national digital health system and My Health Record makes up an important part of this system," Ms Ley said.

"Ms Kruk has held several significant public service positions at the state and federal government level in health and environment, most recently, as chief executive of the National Mental Health Commission.

"The implementation taskforce steering committee will design, implement and oversee the transition of functions and resources from the Department of Health and the National e-Health Transition Authority to the Australian Commission for eHealth.

"The Australian Commission for eHealth will simplify and streamline the current governance arrangements and will ensure better accountability, greater transparency and improve stakeholder engagement throughout."

The Australian Commission for eHealth will also oversee the operation and evolution of national electronic health systems and will be the system operator of the My Health Record System.

Ms Ley said next year, the Government will conduct trials of different participation arrangements for My Health Record, including opt-out, to identify the best approaches for increasing participation in the national digital health system.

"It's important that all Australians are signed up to ensure we have a functioning system and trialling an opt-out model means we can do it carefully, methodically and ensure the appropriate protections are in place to give patients peace of mind," Ms Ley said.

"If automatic registration for a digital health record in the opt-out trials leads to higher participation in the My Health Record system, the Government will consider adopting opt-out on a national scale."

The Health Legislation Amendment (eHealth) Bill 2015 was introduced to Parliament recently and includes the allowance of opt-out trials of the My Health Record system to be conducted.

MyABDR update

From the HFA and National Blood Authority MyABDR Team

WHAT'S NEW?

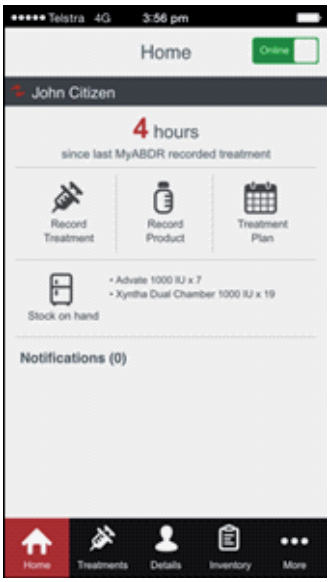
A new version of the MyABDR app was released in August 2015, bringing you more improvements and features:
• Faster synchronisation
• Access to your HTC contacts and Help pages without needing a data connection
• Bug fixes to prevent any duplicate stock and treatment entries, and to tweak the time 'since last MyABDR recorded treatment' timer and the default treatment day.

These changes are all in response to user feedback over the last few months.
Make sure you update your MyABDR app to take advantage of these new enhancements and fixes!

NEED HELP?
Don't hesitate to contact the MyABDR Support team with any queries. Meghan, Danny, Lachlan or Rebecca are available 24/7 and will be happy to assist you.
T: 13 000 BLOOD / 13 000 25663
E: myabdr@blood.gov.au
Available 24 hrs a day, 7 days a week.

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

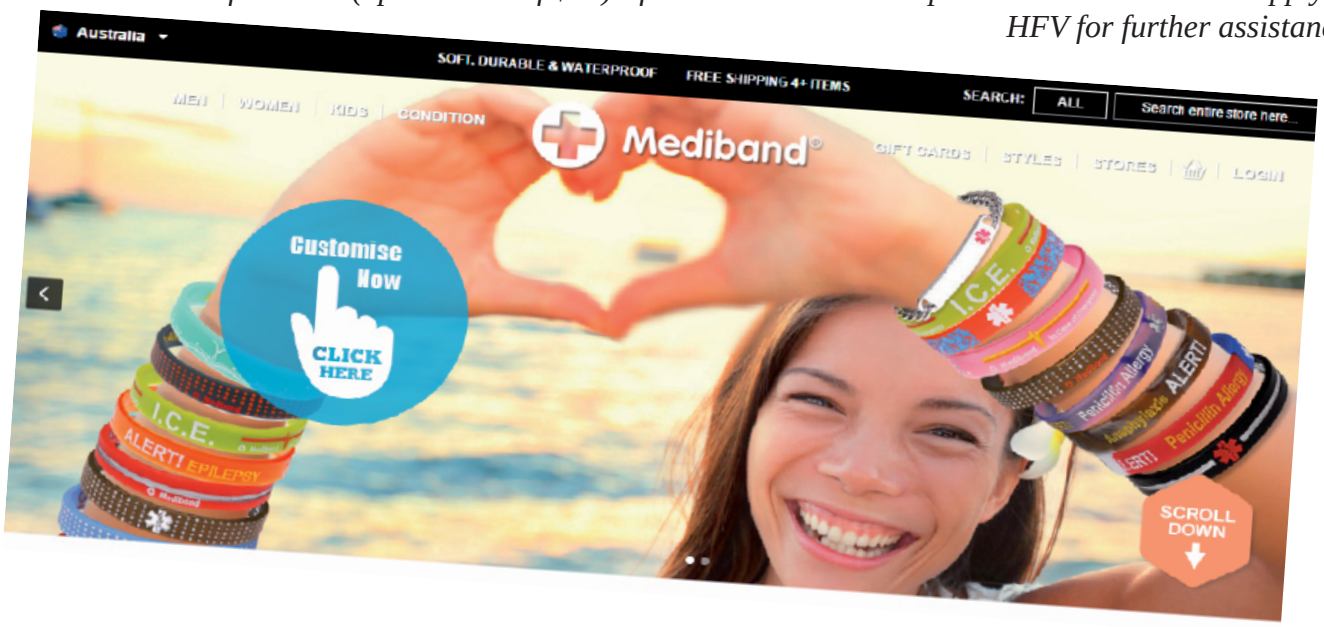
MYABDR FUTURE PLANS
The next release of MyABDR will be available in mid-October, and will include the ability for users to request their own updated emergency card and whether they would like it sent to their Haemophilia Treatment Centre or direct to their nominated delivery address.
This update in October will also further streamline the treatment recording process to make it even easier to add in treatments.



Looking for a medical alert band?

Mediband have a good variety and are very reasonably priced.
For more information go to www.mediband.com

And don't forget as part of your HFV membership benefits you are entitled to a reimbursement of 50% of the cost (up to a max of $30). If the cost still remains prohibitive members can apply to HFV for further assistance.



Healthy Living Apps

Mobile apps are tools that can help us make informed decisions about our health. Many of us have used one of the hundreds of health and wellbeing apps available in online app stores. But how effective are these apps?

WHICH APPS? – Selecting healthy living apps

We looked at over 200 healthy living apps available for Apple® and Android™ devices between May and August 2015. Selected apps were reviewed to see if they were likely to help users change their behaviour and achieve a healthier lifestyle. As well as reviewing the potential effectiveness of apps we have rated them and will update those ratings annually. Read more about how apps were selected, reviewed and rated.

https://www.vichealth.vic.gov.au/media-and-resources/vichealth-apps/healthy-living-apps

HFV Peer Network Training Workshop

At the end of August HFV staff were joined by some committee and other HFV members at the Novotel in Creswick for a Peer Support Training Workshop.

HFV had applied for funding to run this program through the Health Conditions Support Grant and had successfully secured the grant

This workshop was the first session in a comprehensive Peer Support Training initiative. The aim of this workshop was to train HFV members to be part of the initial HFV Peer Support Network - a network of Peer Support Volunteers in regions throughout Victoria and the metro area.

The aim of the workshop was two-fold. We wanted to adequately train our members who already held peer support positions, such as those who run our youth, grandparent's, women's and men's programs and those who have shown interested in peer programs. We also saw this as a really important opportunity for HFV to train regionally and rurally based members to become Peer Support Volunteers for their local communities and expand our reach across Victoria.

During the workshop there were very interesting conversations and observations and it became apparent that HFV is already well equipped with knowledgeably and vested members, many of whom have been in unofficial peer support roles. The benefit of this training was to up-skill participants so they have the confidence to continue their roles in an official capacity and to feel supported by HFV and the wider Peer Support Network.

Now that the first stage of training has been completed, participants have been asked to complete an online course developed by the Chronic Illness Alliance called PLOT (Peer Leaders Online Training).

HFV is planning a follow up training session in early 2016. If you are interested in participating in this network, please contact Julia. julia@hfv.org.au

Ladies Day 2015...BOLLYWOOD STYLE

We had a really fun day out for the 2015 Ladies Day Out. As always I like to try different activities and this time was certainly different. The first thing we discovered was that Bollywood moves don't improve your dancing skills at all! It was a good laugh though. Costumes were fabulous and we all worked up a bit of a sweat accompanied by lots of laughter!

Lunch was really great and we all had plenty to eat. The area they had us in was terrific and we were the only ones in the whole place so it was easy to talk to each other without a lot of background noise. This was a really important part of the day - when we all get to chat about life, the challenges, the rewards and all that's in between. We can connect as partners, parents, daughters and carriers. We are all connected and come away from these events feeling supported by each other.

If you haven't yet attended a Ladies Day Out event we'd really love to see you at next years event. Keep in eye out for the information in the magazines and on the HFV website. We usually hold the day in October and we really love to see new faces.

Julie Boal

HFV FAMILY CAMP 2016

SAVE THE DATE.....Fri 1st to Sun 3rd April

Location: Forest Edge, Neerim East

Check out thier website to see this beautiful and peaceful location: www.forestedge.cyc.org.au/

We hope you can join us for this wonderful camp and share this experience with other families from our community.

our community

HFV REMEMBRANCE SERVICE

Our HFV committee warmly invite our members to attend a Remembrance Service to be led by Neil Boal at the Ian Potter Children's Garden Royal Botanic Gardens on Sunday 29th November at 10am.

This is intended to be a respectful but informal service. The service will run for approximately 15 minutes and will be an opportunity for us to celebrate the lives of all those we've lost in our community throughout the years and to share our memories.

Please also join us for our annual Family Christmas Picnic (and AGM) that will follow the service.

What's new at HFV?

Committee: Our new committee will be elected at our AGM on Sundat 29th November 2015.

Sub-committees: What are sub-committees? These are small groups of members that report to the main committee. They are usually project based so there is a start and finish and the commitment is limited. It's a great way to get involved in your foundation for time poor people. We currently have camp and marketing/communications sub-committees. If you are interested in being part of these or have suggestions for future sub committees please let us know.

Magazine: The HFV committee will be revisiting when the distributed times of 'The Missing Factor' as we are trying to link into other activities across HFV. Members will be notified of any changes in due course.

Christmas Cards - We have decided not to print HFV Christmas cards this year as sales have dropped. HOWEVER we do still have an assortment of cards from previous years so please call the office if you would like to order some ($5 per pack while stocks last). If you would like to see HFV Christmas Cards available for sale again please let us know as we will certainly be reconsidering Christmas cards for 2016 if there is demand. Please phone 03 9555 7595 or email info@hfv.org.au

HAEMOPHILIA CENTRES

Henry Ekert Haemophilia Treatment Centre

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

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Julia Ekert | Office Data & Product Manager
Melinda Cumming | Social Worker

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

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

HFV EXTENDED OFFICE CLOSURE

The HFV office will be closed from 12pm on Wed 23rd Dec — 8.30am on Mon 18th Jan.

Staff will be contactable through email on info@hfv.org.au and phone messages will be checked regularly (03 9555 7595)

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
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:	www.hfv.org.au
Email:	info@hfv.org.au

Haemophilia Awareness Week Celebrations!

2015 HFV Family Christmas Picnic

BOOKINGS ESSENTIAL through the HFV office

Royal Botanic Gardens Melbourne
Sunday 29th Nov

Commencing at 10.30am in the Ian Potter Children's Garden

State Government Victoria

Haemophilia Foundation Victoria Inc acknowledges the support of the Victorian Government.

Registered No: A0011460L