

# THE MISSING FACTOR

*HFV — An interesting journey,  
new challenges & lifelong friends...*

*From the Congress:  
Thinking of self-care  
in a new way*



ASHA KIRA...

A ray of hope and passion for life  
in Manipal, India

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## DIARY DATES

Shepparton Regional Visit	25th Sept
Haemophilia Awareness Week	9-15th Oct
Dads Event	TBC
Ladies Day	23rd Oct
Christmas Picnic @ Scienceworks	27th Nov
Youth Camp	9-11th Dec
HFV Family Camp 2017	28-30 April
HFV RED Ball	OCT 2017
National Haemophilia Conference Melb	OCT 2017

## Committee of Management

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## A word from *our* president, Leonie Demos

Winter is nearly over and thankfully Spring is soon to be here. As the weather starts to warm up it is a time to venture outside more and enjoy the company of others. HFV would like to think that some of that enjoyment can be at one of our upcoming events. On 25th September some of the committee are heading to Shepparton to meet some of our rural families to share a meal and a chat. If you are able to join us we would love to have your company. As well as the regional visits we also have many exciting things as we plan for the Blood Brothers camp, the end of year picnic/AGM and the Ladies Day out. We hope to see you at any or all of these important events on our calendar.

Despite the cold winter the committee have been busy behind the scenes as always working hard. We have met with both HTC's in recent weeks with some very positive outcomes to improve things for our members. HFV will be hosting a focus group as part of a small project looking at ways to improve transition into HTC's for both young people and those families joining us from interstate or overseas. If you have an experience you would be happy to share please contact the office to see how you can contribute to this exciting opportunity to make a difference - all discussions will be confidential and deidentified by HFV.

Make sure you check out a copy of the new Female Factor magazine. It is a fantastic resource and one that I am sure many women within our community will benefit from and find very useful in discussion with their health professionals. Many thanks to all that contributed and to Suzanne and the HFA team for responding to a need that was clearly identified by our members.

As President I have the privilege to represent HFV at the National Council. At the recent meeting there was many things to discuss and much excitement about new products and improvements to care from the World Congress. Very exciting times indeed. With amazing outcomes for our community through Hep C treatments and the many trials of long lasting products it is indeed exciting times ahead. However it is just as critical to stay strong as an organisation and to work with other states and through HFA to ensure our members will benefit from these developments in years to come. As always HFV needs your support to stay connected and remain relevant as we face the future together and all the challenges it will bring.

Good luck with your planned activities for October as we head into Red Cake Day. Hope you are able to host a gathering or at least have some fun with your family making red cupcakes. For those hosting an event we say thank you for your support and whether you are planning to host a morning tea or paint the town red HFV need your support to raise some funds, continue to raise awareness of the issues impacting on our members and hopefully have a lot of fun as well.

Enjoy your read of another bumper newsletter and hope to see you soon at one of the HFV events as we all come out of hibernation and enjoy some spring sun and blossom.

Leonie Demos

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

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





## The Female Factors

*An update on the HFA women and girls project*

### NEW HFA BOOKLET FOR WOMEN AND GIRLS

The first The Female Factors resource is now available – an introductory booklet called ***A snapshot of bleeding disorders in females***. Ask your Foundation or HFA for a copy, or download it from the HFA website – [www.haemophilia.org.au](http://www.haemophilia.org.au).

Next, there will be a series of more detailed information resources on specific topics. They will include personal stories and tips. One suite is targeted at adult women and the other is for young women and teenage girls. The resources cover:

- Haemophilia: carrying the gene
- Living with a bleeding disorder from a female perspective

### WHAT IS THE FEMALE FACTORS?

**The Female Factors** is the HFA women and girls project. The project is developing specific information resources for Australian women and girls affected by bleeding disorders to:

- **Increase their understanding** of their bleeding disorder, treatments and care
- **Help them to feel more connected** with each other by sharing personal stories and tips with others in similar situations
- **Develop high quality, evidence-based information** that they can show to other doctors, nurses, etc who provide their care.

### WHY THE NEED?

What are the experiences of women and girls affected by bleeding disorders? HFA's consultation has found that many have been treated in the community, for example, by a GP rather than a Haemophilia Centre. However, most doctors have not received training about managing bleeding disorders. As a result many women have had problems with diagnosis and referral, and had bleeding problems with surgery, medical and dental procedures, with menstruation (periods) and after childbirth. Many women also spoke about their difficulties in being 'taken seriously' by health professionals, as some of their treating doctors held the belief that women cannot have a bleeding disorder. This is similar to the experience of women with bleeding disorders in other developed countries such as Canada.<sup>1,2</sup>

For these women, feelings of isolation are common.

### WANT TO BE INVOLVED?

You can contribute to the project by joining the HFA women and girls review groups: tell your story, and/or comment on the draft resources. Contact Suzanne at HFA on [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) (women) or Hannah on [hopeskin@haemophilia.org.au](mailto:hopeskin@haemophilia.org.au) (young women and teenage girls); or phone 1800 807 173.

### MORE INFORMATION

Contact HFA T: 1800 807 173 E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) W: [www.haemophilia.org.au](http://www.haemophilia.org.au)

### REFERENCES

1. Haemophilia Foundation Australia. Women and bleeding disorders project report. Unpublished report, Melbourne, 2002.

2. Renault, NK, Howell, RE, Robinson, S, et al. Qualitative assessment of the emotional and behavioural responses of haemophilia A carriers to negative experiences in their medical care. Haemophilia 2011;17:237-245.

the**female**facto**rs**

# A snapshot of bleeding disorders in females

Information for women



## Haemophilia - carrying the gene

### What does it mean to "carry the gene"?

Everyone has the genes responsible for making factor VIII (8) and factor IX (9). These factors are necessary for blood to clot.

Haemophilia is caused by a mutation in the factor VIII (haemophilia A) or IX gene (haemophilia B). This altered gene is commonly called the "haemophilia gene".

If you are a female who "carries the gene" or a male with haemophilia, you will have a genetic alteration

in your factor VIII or IX gene and can pass this altered gene on to your children.

Haemophilia is inherited and occurs in families, where the altered gene is passed down from parent to child. However, about one third of all cases appear in families with no previous history of the disorder. This happens when a new genetic mutation occurs during reproduction. The child who is conceived will carry the altered gene or will have haemophilia.

If someone is diagnosed with haemophilia or as carrying the gene, it is likely that other members of their family also have haemophilia or carry the gene. Diagnosis will also include checking the family history for bleeding problems. Other family members, including females, may also need to be tested for haemophilia.



HAEMOPHILIA FOUNDATION AUSTRALIA

A copy of this information brochure has been included with this magazine.  
If you require more copies please contact HFA on 9885-7800

## An interesting journey, new challenges & lifelong friends...

*Ann Roberts has been an integral member of our Haemophilia community for over 28 years. She has been a committee member and held positions of treasurer, vice president and president for many years. Ann has represented HFV on a national level as a delegate to HFA and has represented HFV and HFA at numerous congresses and also been on the World Federation Haemophilia steering committee. Ann stepped down from our committee last year to dedicate more time to her family and managing their business. I sat down one afternoon with Ann to hear her story and to understand what HFV means to her.*

Our journey with haemophilia began with the arrival of Andrew in 1982. Andrew was our fourth child and became a brother to James (13), Darren (12) and Dale (8). When Andrew started crawling we noticed bruising and swelling and that's when our doctors' visits started. There were numerous appointments until Andrew was incorrectly diagnosed with juvenile arthritis after he was unable to stand or bear weight on his leg. Eventually we found paediatrician Dr David Bannister who after telling him the reason why we were seeing him and of course not a bruise in sight, said that if I thought there was something wrong then there most likely was, as mothers know their children. We were sent to the Royal Children's Hospital for tests for Christmas Disease and Haemophilia. I clearly remember wondering what on earth was Christmas disease was!

It was a week or so before Christmas when the tests results came back from the RCH to Dr Bannister. This was the first we had heard about haemophilia and were shocked to receive a phone call from Dr Bannister confirming the diagnosis. As the RCH closed for Christmas period and he was leaving the next morning on holidays he thought it better that we knew and advised us what to do if we suspected a bleed. We just had to handle the diagnosis as best we could. The initial impact of haemophilia was awful as there was no information available to us. Our family had no history of haemophilia or understanding so we spent that week at libraries

researching anything and everything we could related to haemophilia. Information back then was so outdated and limited I remember thinking no family should be going through this – there should be good information available, which was one of the reasons we became involved with the Foundation down the track.

The first three years were a bit of a blur. Danny was working full time so I took on the role of primary care giver for Andrew. Our older boys just stepped up from the moment of Andrew's diagnosis. Danny was working long hours and I spent time caring for Andrew at home but much of my time was at the hospital as treatment back then was on-demand. James and Darren managed themselves and looked after Dale and they never complained. We all relied on each other to work together and are no doubt stronger because of it. Sadly I can't remember my middle son's teenage years, a tribute to him really as he turned out to be such a great person – our baby daughters 'Buddy Boy'.

When Andrew was 5 he developed inhibitors which of course meant longer stays in hospital. This was another blow for us as a family but we had no choice but to deal with it. Andrew did have inhibitors for a few years but I believe he was the 2nd child in Australia to be tolerised which was a huge relief.

It was around this time when we felt that we had a handle on haemophilia that we decided as a family



we would like to adopt a child with haemophilia. We felt our knowledge would put us in good stead for a child with haemophilia so we began the adoption process. As it happened the social workers thought better so when the time to collect our new addition, it was a baby girl - without a bleeding disorder, that really needed a home. We all embraced our new 6 week old baby into our lives. Chantel was adored by all the boys, they just loved having a sister and she was a good distraction from the countless hospital visits and also took some of the attention away from Andrew which was a blessing for him.

Unfortunately Andrew missed a fair amount of school. One year he missed a third of the year with various hospital admissions. He also felt that he was prevented from participating in certain activities due to his condition, which was both disheartening and frustrating for him.

Andrew had his first infusion whilst



the impact of HIV exposure was hitting the headlines. We were very worried about whether he had received heat treated products so in a way we were very lucky that Andrew wasn't diagnosed until he was 2 as it minimised his risk of contracting HIV. It was a very difficult time for families with haemophilia. People were terrified and didn't want to be identified as having haemophilia due to the connection. We watched the impact on our community, the lives lost and the impact on those families. It was such a tragic time. Andrew coped but looking back he saw friends, his age and older, that he had made through the hospital passing away. We found out much later that for a few years he had thought he had HIV and would also pass away.

The tainted products did change the community. A lot of people were frightened about product safety and where the next problem may occur. A whole section of the community was affected – young and older paid with their lives. At this time HFV received funding to develop services and programs to assist with this crisis but yet again the community was hit with Hep C which had a huge impact again. Some of the same people, others that had missed the first wave of HIV infection now had Hep C. Both HIV and Hep C have had a huge impact on our community. Treatment for HIV is greatly improved now but sadly too late for so many in our community. And the new treatments that are now available for Hep C should change the future for those affected by Hep C. The impact of this tragedy will never be forgotten and the lives of those lost and their families will forever remain in our thoughts and hearts.

By 1988 we had attended a couple of family camps and made some great connections with other families. These families were a great support because they were going through the same issues and we all understood where everyone was coming from. It was also really good for our kids to meet other kids with bleeding disorders and for their siblings. I think it can be easy to

underestimate the impact of a condition on siblings but my other children have definitely been shaped by their brother's condition – shaped positively, but that doesn't detract from the burden they carried. Camp was a particularly good time for us as it brought our family together for the weekend. Although Danny didn't participate in Andrew's treatment at home at the HFV camps all the parents and kids practiced venepuncture on his arms... wow, you wouldn't think of doing such a thing today! We also met other families at the RCH clinic – similar to the multi-disciplinary sessions they now have. This was another good opportunity to make friends with other families or up on the wards if your child had been admitted.

It was this year that we decided we should attend the HFV Annual General Meeting. It was there that Danny, being Danny, volunteered me for the committee. I was happy to be involved as I really wanted newly diagnosed families to have a better introduction to haemophilia than we did. I wanted them to have access to information and access to support and I felt I would be able to assist HFV in improving this and help develop programs. For the first few meetings I sat back and just listened but it wasn't long before I shared my thoughts and after a few years took on roles at an executive level as the vice president, treasurer and president.

One of the eye openers for me was our involvement with the World Federation Haemophilia twinning program. HFV helped establish HAPLOS – and then onto developing a small treatment centre, which led onto other small centres being developed throughout the islands of the Philippines.

My journey with HFV has led onto roles at HFA such as my involvement with World Federation Haemophilia on their Melbourne congress organising committee. Despite the long haul flights, with often only 48 hours in Montreal, my eyes have been opened to the global impact on haemophilia.

Seeing yourself as a member of the global community enable you to see the BIG picture. It motivates you to endeavour to bring treatment to all people with bleeding disorders.

The WFH Congress in Melbourne was a huge opportunity for our members to attend a once in a life time event and benefit from the sessions with world class experts on all aspects of the bleeding disorder treatment, future research on what may come or longer acting treatment. It was an opportunity to see for ourselves that Australia has the best treatment and services in the world today and to be appreciative of that fact. The congress was also an opportunity to bring countries together so they can work on programs to assist third world countries in improving care and assist in lobbying governments for treatment funding.

My hope for HFV and for the bleeding disorders community is that long life products become available that would normalise lives and of course ultimately a cure. Also to recognise our community is constantly evolving and to always be vigilant.

I'm proud to say that over the years all of my family have been involved in some way with HFV. Seeing the effects on families with bleeding disorders we felt that we needed to work together to improve programs and services for all – and it was also a way to help Andrew. So in their own ways and at different times we have all been involved with HFV, HFA as well as WFH.

We all feel, as a family that we have gained more than we have given and we have had and are still having an amazing journey. It has certainly been a different path than we ever dreamed of for ourselves and our children but what a fabulous interesting journey for us all, lifelong friendships, new interests, new challenges – just remarkable. And of course, if it wasn't for haemophilia we wouldn't be blessed with Chantel in our lives and our beautiful grandchild, Peyton.

# ASHA KIRA, a ray of hope

Haemophilia camp is a part of the year I always get excited for. When I think about my time at camp and the lessons that camp helped me learn I find it difficult to imagine the person I would be without it. From the value of my friends, of my community and my own inner strength born of my camp experiences I can only believe that camp has made me stronger. To me camp is more than a weekend away, it's a spirit of strength and hope and love that follows you through your daily life and in the dark and lonely times reminds you of everything you are capable of and that if you fall that there are people out there waiting and ready to catch you.

Since my very first haemophilia camp I have been giving my all to give back and make camp something that can enter the lives of as many people as I can who live their lives effected by a bleeding disorder. Naturally, I was thrilled when I was given the chance to make my efforts international. To give some back story, since 2013 Purple Soup had been running the Asha Kiran family camp in Manipal, India for families in the state of Karnataka with haemophilia in their lives. When I was asked to volunteer my time in this program I knew this was not something I could refuse. It should come as no surprise then that in April of this year I accompanied Ash, Timbo and Penny from the HTC, travelling to Manipal, ready to change some lives.

This was not my first time travelling overseas, having been over to the USA last year, so there were many things I was prepared for; my factor was packed, my treatment plan ready, the necessary documentation signed and prepared should it be needed. What I was not prepared for was how India would be an experience like nothing I had ever experienced. From the moment I stepped off the plane I was hit by a wave of humidity and heat that match as the perfect metaphor for what I felt when I stepped outside of the airport. The sounds, smells and sights hit me like a physical wave of the new and unexpected. Stark contrasts between the browns of the dirt and sand,

green of the surrounding jungle and the roads alive with a rainbow of vehicles that varied in colours, models, age and function.

The roads themselves were lined with buildings, some bright and new, others run down and falling apart yet still alive with people within them making their lives work. Every turn in the road saw new and exciting things and despite my growing exhaustion deep down I didn't want it to ever end.

I'll admit that I went into this experience expecting to be challenged rather than have fun. I expected a lot of caution, children and families scared and sad, sporting debilitating bleeds that made their lives miserable. Because of this we decided it was worth discussing whether or not I should tell them all that I had haemophilia like them, in case all it did was remind them of how much easier we had it in Australia. As the first day of camp began I was nervous; we were standing in a school hall in sweltering heat and I had decided that the families in front of me deserved my honesty and the right to decide for themselves what my 'secret' meant to them. As I listened to the translator tell the families who I was, how so many of us share this common factor (or rather lack thereof) and how I was attending not only as a Souper but representing HFV it was difficult to tell how they took it. My question was answered not long after the ceremony ended when I was approached by campers coming to offer me their appreciation for coming to be with them and their excitement to meet yet another person with haemophilia just like them. My expectations in the end were proven very wrong; the bleeds were there and so was the fear, as it is in us all, but there was also a passion for life and for fun, an appreciation for what they had and that true spirit of camp I had come to love so deeply. The three days I spent at the camp were indeed a challenge, but also so much fun; we all ate together, played together, sang together and laughed together, and while I learnt a lot about our differences they were not as important as the ways we were all the same.

The Asha Kiran camp ended Sunday, just like camps do here, with a ceremony and photo slide show. Every kid left with a trophy from the Silly Olympics we had run





the day before; I shook each hand personally before handing it over. The ceremony also involved songs and dancing from the kids, a speech from a government official and a special thank you for Timbo, Ash, Penny and I. This was much appreciated but not nearly as special as the personal thanks, handshakes, photos and hugs from the campers before we left, along with a few semi-harassing attempts to make me promise to be back next year (no promises but I'll give it my all!).

The next few days of the trip Ash, Timbo and I travelled around and saw some amazing things but this pales in comparison to my experience at Asha Kiran. As I write this article I do realise that by getting my story second hand you can't feel exactly what I am

feeling as I look back. I do however believe that if you know what camp feels like then you get the basic idea. If you are reading and don't know what camp feels like then please do check out a HFV camp, at least once, even if you think it may not be exactly your thing. There is so much that camp has to offer that just can't be written on emails, pamphlets or newsletter articles of another person's experiences. I guarantee you wouldn't be the first person to be surprised at what camp can be, and more often than not that is Asha Kiran, or to translate; a ray of hope.

— Ben Inglis, HFV Committee Member & Youth Leader

\* An inspiring article by Penny McCarthy, Clinical Nurse at The Alfred, who also participated on this trip has been featured in the June edition of the HFA magazine Penny discusses haemophilia care in Manupal, through the eyes of their extremely dedicated staff, highlighting that they 'focus on what we have, not what we don't have'.

[www.haemophilia.org.au/publications/national-haemophilia/2016/no-194-june-2016](http://www.haemophilia.org.au/publications/national-haemophilia/2016/no-194-june-2016)






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## BLOOD BROTHERS YOUTH CAMP

Friday 9th ~ Sunday 11th December 2016

### @ The BRIARS MOUNT MARtha



Friday afternoon to Sunday afternoon,  
...all your food & accommodation provided,  
we've even organized some transport to  
help you get there and back again!

- High Ropes
- Short Film Making
- Sea Kayaking
- Laser Skirmish
- Stand Up Paddle boarding

FACILITATED BY  
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From the  
congress...



THE LARGEST INTERNATIONAL  
MEETING FOR THE GLOBAL  
BLEEDING DISORDERS COMMUNITY

ORLANDO, USA • JULY 24-28, 2016

ORGANIZED BY: WORLD FEDERATION OF HEMOPHILIA  
HOSTED BY: NATIONAL HEMOPHILIA FOUNDATION

## Think of self-care in a new way

*Patrick Lynch formed a company, Believe Unlimited, and created an online comedy series styled after the TV show “The Office.” Dubbed “Stop the Bleeding,” the series—available at [stbhemmo.com](http://stbhemmo.com)—is a mockumentary about a dysfunctional bleeding-disorders nonprofit organization. It uses humour to tackle serious topics like self-care and self-infusion, women with bleeding disorders and the history of haemophilia.*



In 2007, Patrick Lynch’s younger brother, Adam, died of an intracranial bleed at age 18. Both Patrick and Adam were born with severe haemophilia A.

Patrick was only 22 at the time. “As you can imagine, the months and, quite frankly, the years that followed were challenging. I remember saying, ‘[Haemophilia] got him. It’s not supposed to happen to us anymore, but it got him,’” Patrick said during the Wednesday morning “Empowerment Through Self-Care” plenary.

Desperate to discover why Adam died, Patrick searched for a clue. He found it in the bottom of a duffel bag buried in a corner in Adam’s college dorm room. The bag was full of factor. Patrick suspects his brother had stopped his prophylaxis.

“I spent a considerable amount of time thinking about why he fell off his regimen,” Patrick said. “I finally determined that it was because my brother never identified as having a bleeding disorder. That took him off his regimen.”

Patrick has never felt the same way. He developed an inhibitor as a child, but immune tolerance induction eradicated it when he was 13. He was able to go on prophylaxis and live, as he refers to it, “A much more empowered life.” He got involved in high school theatre and majored in acting at Boston University.

Patrick has always valued self-care for his haemophilia, but Adam’s death made him realize that others—particularly children—may not.

“It made me think about how we as a community are engaging young people,” he said. “And I saw an opportunity to use my acting background to create something that didn’t exist.” His brother didn’t connect to the bleeding disorders community in traditional ways, but like



many young people, he loved comedy and the internet.

So Patrick formed a company, Believe Unlimited, and created an online comedy series styled after the TV show “The Office.” Dubbed “Stop the Bleeding,” the series—available at [stbhemmo.com](http://stbhemmo.com)—is a mockumentary about a dysfunctional bleeding-disorders nonprofit organization. It uses humour to tackle serious topics like self-care and self-infusion, women with bleeding disorders and the history of haemophilia.

“We want to teach young people with a bleeding disorder, but we really want to inspire them,” Patrick said. The goal is to replace the stigma and fear of haemophilia with the idea that the disease can be “Funny or cool or even uplifting,” he said.

Since launching “Stop the Bleeding”, Patrick’s company has also created a live speaker series called “Powering Through”; the Impact Awards to recognize teens with bleeding disorders; a monthly podcast called “Bloodstream” and a claymation series called “Helping Hany” that examines the psychosocial implications of being a girl with a bleeding disorder. He’s also produced videos for the WFH Treatment for All initiative.

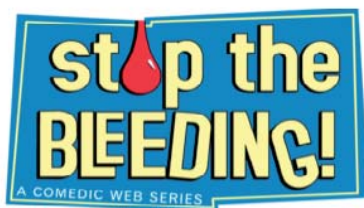
All of this fits within Patrick’s definition of self-care. “My journey and understanding of self-care has evolved,” he said. “It’s not just self-infusing, stretching, and maintaining a good diet. For me, self-care is giving back to

and empowering the community.”

He also acknowledges that he has a “Privileged definition of self-care—a privilege not shared by 75 percent of our community in developing nations.” That’s why he believes people from the developed world have an obligation to help others who aren’t able to self-infuse or do other aspects of self-care because they lack treatment options. This can include asking product manufacturers how they help people in developing countries and contributing to the WFH Humanitarian Aid Program.

“I miss my brother. For years, I thought about him every day,” Patrick said, his voice breaking. “Let’s continue to ramp up our efforts for our brothers and sisters in developing countries so one day they too may enjoy a privileged definition of self-care.”

Reprinted with permission from WFH  
[www.wfh.org](http://www.wfh.org)



## Welcome to Stop The Bleeding!

*Stop The Bleeding! (STB!)* is an award-winning comedic, mockumentary-styled web series about a dysfunctional non-profit organization that serves the bleeding disorders community.

Created by actor/writer + severe hemophiliac Patrick James Lynch in the wake of his teen brother's hemophilia-related death, *STB!* aims to strengthen and expand the online community of people with bleeding disorders by using comedy + video as tools of engagement, advocacy, + outreach.



# 2016 WFH Congress Reports

By David Stephenson

## Extreme Sports for those with Haemophilia

It was an interesting presentation at 2016 WFH about a group of haemophilia men who's aim was to run a New York marathon. The medical team who also took part in the run looked after the participants like Olympic athletes with a staged preparation plan that built strength, endurance and muscle. An interesting rule for the marathon was that no treatment was allowed during the run, so to manage this, some of the men (all were mild / moderate haemophilia) topped up with treatment before the run. One of the participants in the preparation phase suffered pain in his hip, he called the doctor involved, they took an xray and discovered a fracture to his femoral head (top of leg) which was then fixed with orthopaedic procedure. After recovery the man still wanted to run the marathon which he did. The medical team were proud of what was achieved, however I was quite disturbed by listening to the whole story – on the one hand it was great to promote achievements and the personal gains for those involved, however its nothing I would encourage, as you are placing people very close to the line of injury (and over in the case of the fracture). When it came to audience questions my concerns were vocalised by some medical professionals, one pointed out the high risk and how this can, and will impact in the future, he indicating that the injured person now faces a future of multiple operations that could have been avoided. One went further indicating that in 'normal people' there is clear evidence that these activities cause problems so why encourage someone with haemophilia.

I asked the team if osteoporosis was a factor in the injury and it was - a not uncommon issue for those with a bleeding condition - have you been checked – go visit your GP so you know your risk factors and boundaries, that's my message to you. Also during the presentation, it was revealed that another mild haemophilia patient (not associated with this project) chose an

even more extreme sport – kick boxing. So to all my fellow sufferers, think twice about extreme sports as the future payback may not be worth it.

## Gene Therapy

As of 2016 there have been 11 haemophilia gene therapy clinical trials of which 6 are currently open. Each of the ongoing trials (phase 1&2) is testing factor VIII & IX. The results so far have been mixed with challenges. There is also a development of a stem cell approach using lentiviral vector for factor VIII. This is a rapidly advancing area and the shared expectation is that transformational advances are on the horizon. Some outcomes have been low level factor improvement where predictably curative FIX levels were achieved and other trials that provided a sustained 25% or more FIX levels. In addition, there is now a question about certain types of gene therapy possibly linked to liver cancer but this is extremely and unclear suppositional and as you expect work continues to investigate safety.

## CSL extended Half Life Product

Australian CSL Behring presented results from the Phase III clinical studies of their recombinant extended half-life factor IX product at the American Society of Haematology meeting in December. The product, rFIX-FP, is a recombinant factor IX fused to recombinant albumin. Albumin is a naturally-occurring plasma protein that has a long half-life in circulation. Linking it to factor IX also gives the factor IX a much longer lifetime in the bloodstream. CSL data from its PROLONG-9FP studies evaluating the efficacy and long-term safety of the product when used for routine prophylaxis at dosing intervals of 7, 10 and 14 days. They also presented efficacy and safety results in patients undergoing surgical procedures. They obtained excellent results with a median annualized bleed rate of zero. They saw no serious adverse reactions and no inhibitor development.

David Stephenson, President HFQ



## HAEMOPHILIA B TRIALS Data Shows UniQure's Gene Therapy Performing well in Haemophilia B Trial

UniQure recently announced data from a phase I/II clinical trial of AMT-060, one of its proprietary gene therapy technologies, to treat patients with haemophilia B (factor IX deficiency). UniQure is an Amsterdam-based company specialising in developing gene therapies to treat rare conditions, such as central nervous system disorders, and liver/metabolic and cardiovascular diseases.

UniQure's haemophilia B technology employs adeno-associated viruses (AAV). These small viruses, which do not cause disease and produce mild immune responses, are used as vectors (delivery vehicles) to introduce a functioning factor IX (FIX) gene into the liver cells of patient's with haemophilia B. The goal of the trial is to trigger long-term FIX protein production through a single administration of the therapy. This could dramatically reduce the frequency of bleeding episodes in people with haemophilia B.

The data were reported via a press release and an oral presentation given by lead investigator Frank Leebeek, MD, PhD, Professor of Hematology at Erasmus University Medical Center in Rotterdam, at the 21st Congress of the European Hematol-

ogy Association (EHA) in Copenhagen, Denmark, June 9-12, 2016. The trial of 10 patients divided them into two groups: five received a low-dose administration of AMT-060 and five received a considerably higher dose. The data presented at the EHA Congress were from the low-dose group.

Before the trial, the five patients in the low-dose group all had FIX activity levels consistent with moderate-to-severe haemophilia B. Their median recorded activity was less than 1.5%, requiring prophylactic infusions of FIX concentrate to control their bleeding. Six months after receiving a single low-dose administration of AMT-060, all five patients showed an increase in FIX activity, with a median level of 5.4%. This seemingly modest increase is significant. It represents a change in severity from primarily severe to mild/moderate, indicating both a notable decrease in spontaneous bleeding and improvement in quality of life.

According to UniQure, AMT-060 has so far been well tolerated by patients in the first group. One patient had a temporary increase in the level of the liver enzyme alanine aminotransferase 10 weeks after receiving the therapy. This was quickly corrected

with a short regimen of the steroid prednisone. In addition, none of the patients developed inhibitor antibodies.

"After six months of follow-up, I can say as a clinician who regularly treats haemophilia patients that the impact on the quality of life for these patients treated with AMT-060 is very positive," said Leebeek. "The increases in FIX activity and the overall stability of the activity observed over a 6-month period are cause for optimism, as they are associated with meaningful clinical benefits as well as reduced need for ongoing infusions of recombinant FIX therapy."

UniQure has also announced that all five patients in the second, high-dose group have received a one-time administration of AMT-060. That dose is four times higher than the one administered to the low-dose group. According to the company's news release, these patients are currently in the early stages of follow-up. Initial data are expected to be presented before the end of 2016.

Press Release

Source: UniQure press release dated June 11, 2016

## Our Grandparents & Friends Get Together

*Proud grandparents and friends enjoyed a lovely lunch and time together to share photos, chatter and lots of laughter.*

*Its always nice to catch up with each other and welcome new grandparents and friends, some who travel from far and wide to make the afternoon so special.*

*Marie.*



# SHOWCASE YOUR EMPLOYABILITY

## Bridging The Gap in Today's Job Market Taken from a case study published by myfuture

Having a university qualification is more important than ever yet Australia's most educated generation are leaving university and now facing the worst job prospects in decades. The reality of today's competitive labour market is that completing a tertiary qualification won't always guarantee a job or even an interview in your specialised field or occupation. Over 30% of recent graduates find themselves still looking for a full time work four months after completing their degree. (Source Graduate Careers Australia 2015)

Whilst an academic track record may demonstrate competence and dedication to achieving a goal the game has changed and it is not the only things today's employers are looking for.

### *Showcase your unique skills and qualities*

The challenge is now the way in which you showcase yourself; as an individual with relevant qualities, qualifications and experiences.

Today's employers from large corporates to entrepreneurial start-ups are looking for well-rounded candidates who also possess skills learnt outside of the classroom. Skills that show you are potentially a proactive, confident and engaged employee who can work in a team and learn and adapt to real life situations.

Finding marketable qualities to put on your resume may not be that challenging especially if you have

been involved in regular activities, volunteering, and other significant projects during your studies.

From amateur sports teams, short film productions to group hiking expeditions and community work, all these can demonstrate your willingness to challenge yourself, persevere, communicate and lead. Attributes which are attractive to employers.

### *Stand out from the crowd*

Skills learnt outside of the classroom translate into key qualities worthy of mention on your CV but ensure you can back them up with real life examples.

Skills and qualities learnt outside the classroom may include

- team work
- problem solving
- communication skills
- goal setting
- resilience
- responsibility
- community service and engagement
- positive contributions to community
- perseverance
- confidence
- decision making
- organisation and planning

Doing activities outside the classroom through internationally recognised programs like the Duke of





Edinburgh's International Award are also important to mention as they are highly regarded by employers globally. So consider all your life outside the classroom as ultimately these activities may be the deal breaker in landing your dream job.

### *Learn how doing the Award made the difference in getting that dream job for Scott*

Recent accounting graduate Scott McCurdo landed his dream job through showcasing his volunteering and community service experiences as part of the Duke of Edinburgh's International Award.

According to the recruiter Scott was selected as he was "the only candidate that had an impeccable record of community service"

### **So demonstrate that you are a well-rounded individual**

That community engagement, volunteering or honing new skills is a challenge that you welcome. Making you not only a unique individual, but a motivated worker who is capable of developing oneself and performing in any environment.

### **Add the Award to your CV and LinkedIn profile**



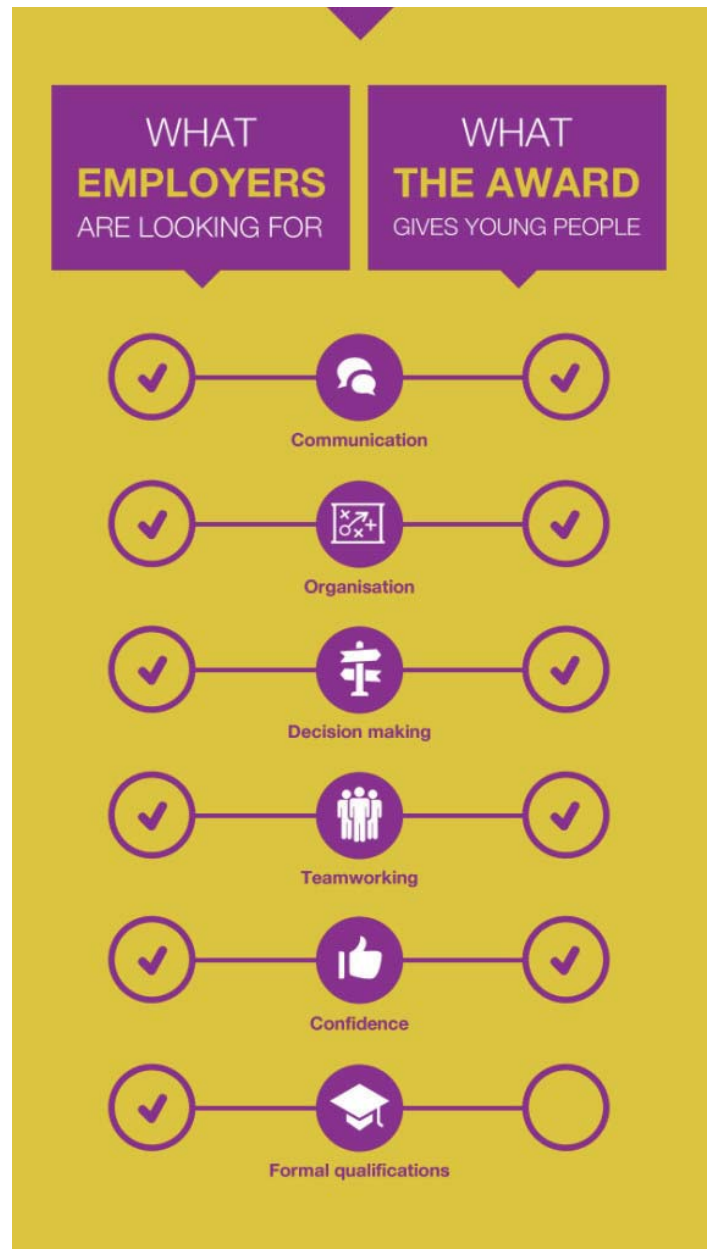
Adding your Award to your CV and LinkedIn profile will enable you to stand out from the crowd. Including the skills you have developed outside of the classroom will demonstrate to employers that you have the qualities they require.

### *Share your Award experiences with employers in interviews*

Use your Award experiences to demonstrate to employers how you learnt key skills. For example, you most likely developed team working, communication and leadership skills on your Adventurous Journey. You probably improved your patience during your Skill section; taking time to learn something new requires dedication, and you may have even surprised yourself with your ability to problem solve whilst carrying out your Service. It's skills and

experiences like these that employers are keen to hear about, so remember to tell them when they ask for examples of how you demonstrate each of these skills and attributes.

[www.dukeofed.com.au](http://www.dukeofed.com.au)



### **Duke of Edinburgh EXPRESSION OF INTEREST**

**HFV, in partnership with Purple Soup is willing to support any HFV youth member, in participating and obtaining The Duke of Edinburgh Award.**

**Please contact Julia on 9555 7595 or [julia@hfv.org.au](mailto:julia@hfv.org.au) to express your interest.**

# NEW ERA IN GENETIC DISEASE DIAGNOSIS

***The Garvan Institute of Medical Research's Kinghorn Centre for Clinical Genomics will launch Australia's first clinical whole-genome sequencing service at an event today in Sydney. This new service could triple the diagnosis rates for Australians living with rare and genetic conditions.***

New era in genetic disease diagnosis with Australia's first whole-genome testing service launched.

The Garvan Institute's Executive Director, Professor John Mattick AO FAA said that the launch will mark a turning point in disease diagnosis and health care in Australia.

"This new service extends cutting edge genomic technology beyond the research lab. We now have the ability to provide answers to many of the hundreds of thousands of Australians affected by genetic disease.

"We are on the precipice of a tremendous revolution in health care. The more we understand about the whole genome, the greater our ability is to make life-changing diagnoses for genetic conditions and help patients receive the right treatment faster.

We are at the forefront of genomic discovery and understanding – it is a very exciting time," Professor Mattick said.

This Australian funded whole-genome sequencing service is the result of a two and a half year

development at the Garvan Institute's Kinghorn Centre for Clinical Genomics in conjunction with NSW Health Pathology - the country's largest provider of public pathology services.

The service will be offered by Genome.One, a newly established health information company that is owned by, and based at, the Garvan Institute of Medical Research in Sydney.

Bill Ferris AC, Chair of Innovation and Science Australia and past Chair of the Garvan Institute, said, "Genome.One is a wonderful example of how the superb medical research and technology in our country can be translated into innovative health advances and real economic benefits."

Patients seeking a diagnosis for a possible genetic condition will be referred to a clinical genetic service who will work with NSW Health Pathology to assess whether whole genome sequencing can provide an answer.

Those who may benefit will then be able to access the service from Genome.One who will screen all 20,000 genes at one time, providing a faster, more accurate and comprehensive service than any other genetic testing in the country.

The new service will be able to help hundreds of thousands of Australians who currently live with a genetic condition, many of which are rare and challenging to diagnose. This new service will increase the diagnosis rates of these conditions from around 20 per cent to 40 – 60 per cent.

Dr Marcel Dinger, Head of the Kinghorn Centre for Clinical Genomics predicts that the impact of this new service will be significant:

"For families, receiving an accurate and timely diagnosis could result in access to new treatments and therapies as well as a clearer understanding of the journey ahead," he said.

"This one test puts an end to the long and complicated journey to diagnosis that at the moment, many families endure. The value the test provides is not confined to benefits to the patient, it will have economic benefits to the health care system as well.

"We are looking forward to working with local and international clinical and research communities to grow our knowledge of the human genome. This will ultimately lead to further breakthroughs and a greater understanding of how each person's unique genome affects their individual health," Dr Dinger added.

The ability to diagnose a rare disease also provides the opportunity for patients and clinicians to connect with others who have the same diagnosis around the country and the world, allowing them to better understand and potentially treat their condition, as well as providing a much needed support network.

Families who are currently searching for a diagnosis of a genetic disease should speak to their genetic specialist about whether Genome.One's new test is appropriate for them.

*Media Release: 27 July 2016*

## ASSISTING IN TRANSITION FROM THE RCH TO THE ALFRED

HFV was recently invited to attend a transition meeting with both The RCH and The Alfred teams to look at ways to improve the transition process for their patients.

HFV is now holding a transition **focus group** at 3pm on **Sunday 2nd October**. This will be held at a restaurant near to the Alfred.

We will have 2 sessions running concurrently in different areas – a parents session and a youth session. Tim Demos will run the youth session and Leonie Demos will lead the parents group. This will be an opportunity to input to the HTC process in a confidential and safe environment. All information will be collated by HFV and identified before sharing with any external stakeholders and only with your permission.

We are looking for families who have recently transitioned or who are soon to be transitioning to attend. If you cannot attend we can simply call you to discuss at a convenient time to you.

Please contact the HFV office on 9555 7595 if you can assist us ASAP. Many thanks.

*...and for those of you with children there is an Adventure Playground just next door to the restaurant.*

*Entrance fee is a good coin donation!*

*So please come along and join us for lunch and enjoy the afternoon at the Adventure Playground. .*

**Do you live in the SHEPPARTON region?**

*Please join us for lunch*

You are invited to join the HFV team and people in YOUR area with haemophilia and other bleeding disorders for lunch and a chat!

Lunch is provided by HFV - so bring your kids, bring your parents.

**ALL INVITED!**

*when : 12pm Sun 25th Sept 2016*

*where: The Connection,  
7287 Midland Highway Shepparton  
(Peter Ross-Edwards Causeway,  
between Mooroopna & Shepparton)*

*Please RSVP by Mon 12th Sept to 9555 7595  
or [info@hfv.org.au](mailto:info@hfv.org.au)*

**BOOKINGS ARE ESSENTIAL**

HAEMOPHILIA FOUNDATION VICTORIA

A HFV Peer Support initiative

**connect support empower**



## WEEKEND RETREAT FOR GUYS WITH HAEMOPHILIA & HIV

29TH SEPT - 2ND OCT

So far 11 guys are attending - it's not too late to join us!!!

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

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

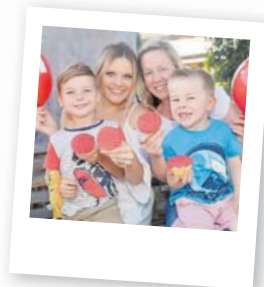
And if you are reading this and you have haemophilia and HIV, then I reckon you should come along – we are all different but we share something that no-one else can truly understand. Even if you don't want to attend, maybe you'd at least consider joining the secret facebook page I've set up to establish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

Just call me to book in or for a chat.

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



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



*We are calling on our friends and supporters to take part in Red Cake Day during Haemophilia Awareness Week!*

**Red Cake Day during Haemophilia Awareness Week** is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign to raise funds and awareness about haemophilia, von Willebrand disorder and other bleeding disorders during the week of **9-15 October 2016**.

To order your free promotional items, download an order form from [www.haemophilia.org.au](http://www.haemophilia.org.au) or email [donate@haemophilia.org.au](mailto:donate@haemophilia.org.au)

GET IN QUICK - STOCKS ARE LIMITED!

#### How can I get involved?

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



Like HFA on Facebook  
[www.facebook.com/RedCakeDay](https://www.facebook.com/RedCakeDay)



Follow HFA @Haemophilia\_Au and join the conversation at #redcakedayhaemophilia



HAEMOPHILIA FOUNDATION AUSTRALIA

For more information on Haemophilia Awareness Week and Red Cake Day, visit [www.haemophilia.org.au](http://www.haemophilia.org.au) or call HFA on 1800 807 173

## Bendigo Bank Supporting Haemophilia Awareness Week NATIONALLY

The HFV committee and staff are thrilled that the Bendigo Bank has agreed to support Haemophilia Awareness Week nationally for the second year running!

- This is a wonderful opportunity to raise awareness and funds for our haemophilia community
- If parents wish to open an account for their child with the Bendigo Bank please mention HFA to the staff member. This will be noted and will assist with a future national focus for our community and continued support from the Bendigo Bank.



## HAEMOPHILIA AWARENESS WEEK (HAW) Fundraising Event CHECKLIST

*Thinking about organising a HAW event but not sure where to start? After running a very successful annual HAW 'Paint the Town Red' event Donna Field has produced this checklist to assist you. If you have any questions or still not quite sure what to do just call our HFV office on 03 9555 7595 and chat with Andrea or Julia.*

### WHAT TYPE OF EVENT AM I COMFORTABLE TO HOLD?

- BBQ, Cupcake Stall where you can also sell red items,
- Hold a Raffle,
- Guess the Lollies in the Jar Competition,
- Bake a Cake and hold a name the Cake competition with the person who decides the best name being someone who has a bleeding disorder,
- Organise a Ball,
- Organise a High Tea,
- Organise a Bike ride or Horse ride,
- Organise a sporting day etc.

The event can be BIG or small it doesn't matter it is all about getting the Awareness out in your community. *You are only limited by your imagination!*

**RAFFLES:** If I hold a raffle will the local businesses or my employer like to contribute to the prizes by donating funds or items? Or sponsor me? Will the Traders and businesses in my local Town/Suburb like to be involved? How do I want this to look like?

**GET PEOPLE INVOLVED:** Which organisations, clubs, and group's do I have an association with and/or will my employer and fellow employee's like to be involved? Will my fellow employees or friends like to help me bake and decorate Cup Cakes? HFA have a list of cake recipes if you need assistance.

**SCHOOLS:** Will my local school Primary School or Secondary College like to be involved and hold a Casual for A Cause Day or hold a Cup Cake stall? HFA can arrange for the appropriate letters to be sent to the Schools.

**DATES:** Which date/s suits me to hold my event on? Can be during Haemophilia Awareness Week or at another time during the year if October doesn't suit.

**MARKETING:** How will I market/communicate my event? Do I need assistance from HFV or HFA? With Local radio stations. Newspapers, Facebook, internet, HFA & HFV newsletters. I will need to order my merchandise through the HFA merchandise link:  
[www.haemophilia.org.au/get-involved/events/red-cake-day](http://www.haemophilia.org.au/get-involved/events/red-cake-day)

**CONTACT YOUR LOCAL MEMBER:** Do I have a local member/s of Parliament I could notify of Haemophilia Awareness Week and my event? They may like to mention HAW in their Parliamentary speaking time.

**Remember to take photos of your event to share with HFA and HFV.**

**BEST OF ALL HAVE FUN!!!!!!!!!!!!!!**

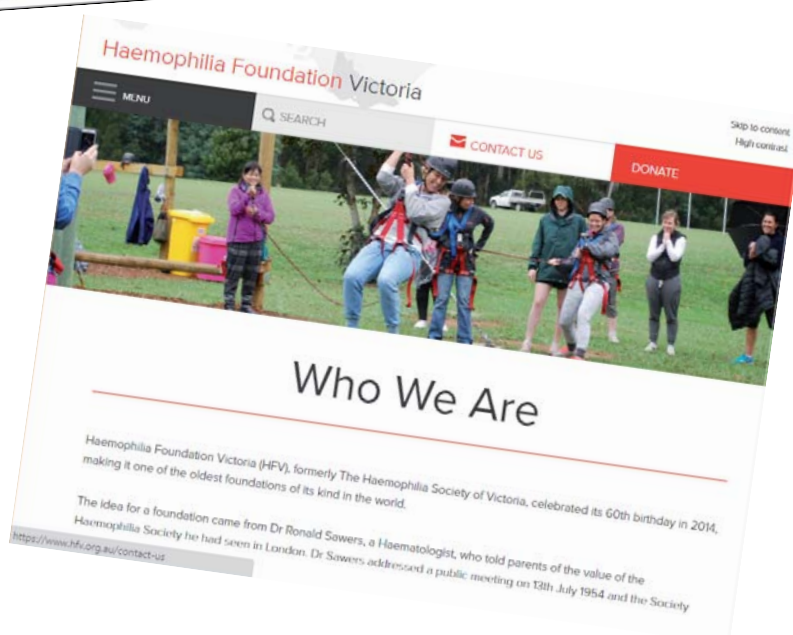
# NEW HFV WEBSITE LAUNCHED...



After many months of work HFV is delighted to announce the launch of our new website.

We have worked in partnership with HFA and our other National State Foundation teams in order to be able to provide uniformed websites that can be integrated with HFA. This means that:

- State foundations and HFA share the same information relating to health conditions
- People can access the HFV website directly through the HFA website
- Events will include both HFV and HFA events



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



## ...an easy way to help support HFV



“Discover thousands of valuable up to 50% off and 2-for-1 offers for many of the best restaurants, cafés, arts, attractions, hotels, travel, shopping and much more – choose your way with the following:

- The traditional Entertainment™ Book Membership that comes with the Gold Card & vouchers.
- The Entertainment™ Digital Membership that puts the value of the Entertainment™ Book into your smartphone! “

**Payment Page: [www.entertainmentbook.com.au/orderbooks/1834x75](http://www.entertainmentbook.com.au/orderbooks/1834x75)**

## **NOhep...** **our next** **greatest achievement**



### **Australia is leading the way for a NOhep future**

Effective viral hepatitis treatments are available  
in Australia. **Change your future today.**  
Talk to your doctor about your  
**treatment options.**

Hepatitis information line  
1800 437 222 (1800 HEP ABC)



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

hepatitis  
australia



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

A sub-committee has been established to raise funds for projects and programs to meet our community needs. We would like to invite you to be PART of this sub-committee by contributing to the organisation of a Charity Ball to be held in 2017.

Please contact us directly if you would like to be part of the team:



1. Marketing Team please email Nicola at [nicolamarks3@outlook.com](mailto:nicolamarks3@outlook.com)
2. Silent Auction Team please email Catherine at [catherine@nobleknight.com.au](mailto:catherine@nobleknight.com.au)
3. Entertainment Team please email Monica at [littledemon5@yahoo.com.au](mailto:littledemon5@yahoo.com.au)

## our community

### Christmas Picnic & AGM 2016 27 NOV @ SCIENCEWORKS



We are heading back to SCIENCEWORKS  
for this years Christmas Picnic & AGM.

We hope you can join us!

10.30am - 2.30pm  
27th November 2016,  
2 BOOKER ST, SPOTSWOOD VIC 3015

Bookings are essential by calling the office on 9555 7595  
or emailing [julia@hfv.org.au](mailto:julia@hfv.org.au)

### HFV LADIES DAY OUT 2016 11am - 3pm Sunday 23 OCT PENINSULA HOT SPRINGS

JOIN US ON THE BEAUTIFUL MORNINGTON PENINSULA FOR A DAY  
OUT AT THE PENINSULA HOT SPRINGS FOLLOWED BY LUNCH IN A  
BEAUTIFUL, PRIVATE, MOROCCAN MARQUEE!



This will be a wonderful opportunity for our well deserving mums, partners, sisters, grandmothers and aunties to enjoy a relaxing day together at the Peninsula Hot Springs - the first natural hot springs and day spa centre in Victoria!

Experience over 20 globally-inspired bathing experiences including a cave pool, reflexology walk, Turkish steam bath, sauna, cold plunge pools, family bathing area, massaging thermal mineral showers and hilltop pool, offering stunning 360 degree views of the region.

Robe & towel included. Please bring bathers.

Address: 30 SPRINGS LANE, FINGAL VIC 3939

Please arrive at 10.45 for an 11am start finishing at 3pm.

Numbers are limited. \$5-\$10 contribution requested (non-compulsory)  
Bookings essential through the HFV on 03 9555 7595 or email [andrea@hfv.org.au](mailto:andrea@hfv.org.au).

### HFV YOUTH

The HFV Youth Leader  
Team is looking for new  
members.

If you're aged between 15  
and 25 then we would love  
to hear from you.

This could be a great op-  
portunity for you to learn  
new skills that can be  
put on your resume but  
we need new members to  
help us decide how our  
team do this.

If you are interested  
please email  
[info@hfv.org.au](mailto:info@hfv.org.au) for any  
further information.

## HAEMOPHILIA CENTRES

### HENRY EKERT

#### HAEMOPHILIA TREATMENT CENTRE

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

Dr Chris Barnes | Director Henry Ekert HTC  
Janine Furmedge | Clinical Nurse Consultant  
Julia Ekert | Office Data & Product Manager  
Nicola Hamilton | Physiotherapist  
Wade Wright | 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](mailto:haemophilia@alfred.org.au)

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

## HFV MEMBER SERVICES

### Membership Fees:

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

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

### Ambulance Subscription Subsidy:

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

### To obtain an Ambulance Subsidy:

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

### Other Subsidies:

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

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

### Care and Counselling:

This is available through your treatment centre.

### Magazine:

Your quarterly magazine offers information and details of upcoming events.

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

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

### The HFV Office:

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

### We are located at:

13 Keith Street,  
Hampton East, Victoria, 3188.

### Phone:

(03) 9555 7595

### Fax:

(03) 9555 7375

### Website:

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

### Email:

[info@hfv.org.au](mailto:info@hfv.org.au)

**SAVE THE DATE!**

**HFV CAMP 2016**

**28 — 30 APRIL 2017**

**CAMP WILKIN,  
ANGLESEA**



*Featuring presentations  
from the Congress*



**WFH 2016  
WORLD  
CONGRESS**

Orlando, USA • July 24-28

**THE LARGEST INTERNATIONAL  
MEETING FOR THE GLOBAL  
BLEEDING DISORDERS COMMUNITY**

**ORLANDO, USA • JULY 24-28, 2016**

ORGANIZED BY: WORLD FEDERATION OF HEMOPHILIA  
HOSTED BY: NATIONAL HEMOPHILIA FOUNDATION

...If you have ever attended a HFV camp or event we are sure you will enjoy watching this series! It is a very funny web series, exceptionally well produced, about all the dramas that go on at a dysfunctional haemophilia organisation BUT highlights the more serious issues faced for people with bleeding disorders. It is definitely worth a look!

The HFV Team



**stop the  
BLEEDING!**

A COMEDIC WEB SERIES from BELIEVE DIGI

[www.stbhemo.com](http://www.stbhemo.com)

EPIISODES   ACTIVITY BOOK   STB EN ESPANOL!   MORE STUFF!   GALLERY   ABOUT