

THE MISSING FACTOR



POSTER SESSIONS
Now available online

**DRUG &
ALCOHOL
INFO**

**For Young People with
Bleeding Disorders**



**Women
Affected by
Bleeding
Disorders**



© Normadesmond / Dreamstime.com / Women's Symbol Photo

contents

cover

stories

- 4 Drug and Alcohol Information for Young People with Bleeding Disorders
- 6 Women Affected by Bleeding Disorders
- 13 WFH Posters
- 24 Blood, Sweat and Gears

our

features

- 7 Hep C News
- 9 New Era for Haemophilia Treatment
- 10 John Pharo - *AKA Lord P of Chiswick & The Absent Minded Professor*
- 12 AIDS Conference 2014
Bill Clinton addresses the delegates
- 14 Ladies Day - *10 year celebration!*
- 17 Make a Move...and improve the lives of those with MSK conditions
- 19 Addressing Australia's Skills Shortage

hfv

team

- 3 President's Report
- 13 Message from Leonie Demos
- 15 2015 Family Camp

Haemophilia Foundation Victoria Inc

ABN: 67 922 470 900

13 Keith Street, Hampton East, VIC 3188

Patron: The Honourable Alex Chernov, AC, QC

Governor of Victoria

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

AGM and Christmas Picnic — 9th Nov

2014 Family Camp — 22 & 23rd Nov

2015 Family Camp — 27 to 29th March

2015 Men's Retreat — April TBC

2015 Blood Brothers Camp — April TBC

A message from *your* president, Ann Roberts

Committee of Management

President

Ann Roberts

Vice President

Jodie Caris

Treasurer

Zev Fishman

Executive Member

Leonie Demos

General Committee

Matthew Blogg

Karen Donaldson

Carol Ebert

Donna Field

Sharron Inglis

Michelle Sullivan

Damian Wensing

Another busy few months have passed by very quickly. We have had our annual Grandparents and Friends get-together. It was great to see our regulars there and wonderful to meet our first-timers!

Haemophilia Awareness Week was celebrated around Australia and there were many local promotions run around Victoria by members. Thank you to all those involved in raising awareness of haemophilia during this important week.

The Ladies Day group were treated to an extra special event this time to help celebrate their 10th anniversary! The ladies headed to Prahran and enjoyed a relaxing and well-earned massage and followed on with a lovely lunch. As always, it was a wonderful opportunity for our ladies, whether they be mothers, partners, sisters, grandparents or friends, they all play a vital role on the lives of someone affected by a bleeding disorder, and they all benefit from the peer support provided at these events.

As we head closer to Christmas things here at HFV are not slowing down. We have our annual Christmas Picnic and AGM booked for the 9th November. This is being held at Bicentennial Park in Chelsea. It really is an amazing award-winning park that the kids will love so if you are free please join us. IT is BYO picnic and there will be face painting and balloon animals provided by HFV.

Also, in November we have our 2014 Family Camp. This is usu-

ally held in March but due to the World Haemophilia Congress being held in Melbourne this year it was postponed. We are really excited about this particular camp as we now have a camp sub-committee that have been very proactive and have set up an extensive program that will have a lot more member involvement - particularly from our youth. Purple Soup will be joining us for Saturday and will be running some of their fantastic programs. We also have the RCH team attending on the Sunday morning to run a session for families who attend the Children's. We have had a great response so far with many families booked in. If you have missed out on booking you are still welcome to join us for a day but please contact the office to confirm. We also have another family camp booked for March 2015!

After many years of holding our HFV Christmas Lunch / Dinner we have decided not to run it this year. Our numbers have certainly dwindled over the last few years and we know it is often difficult for people to attend with their work and family commitments - especially at this busy time. We are hoping our members who often attended the Christmas Lunch/ Dinner will join our committee and staff at our AGM and family picnic on the 9th November.

If I do not see you at any of our upcoming events, I wish you a happy and peaceful holiday season.

Ann

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.

Drug and Alcohol Information for Young People with Bleeding Disorders

As you get older your social life often gets bigger and doesn't always have mum, dad or other family members involved. With this increased social life comes the potential for exposure to activities, such as drinking alcohol and other drug use. Most people use some kind of legal drugs – alcohol, prescribed medications and caffeine are part of everyday life for many of us.

You have to be 18 to legally use alcohol and tobacco in Queensland (and Victoria). The use of recreational drugs, such as marijuana, 'ice', etc., is illegal and can result in serious legal consequences. Using illegal (illicit) drugs is a part of life for some of the people you may meet as you socialise, so it is important that children and teens know about the impact and possible dangers of alcohol and drugs as much as adults.

There are also additional risks from drinking and drug use to individuals with a bleeding disorder. Did you know that being out of it can make infusions more difficult to perform?

And remember that it's always OK to say no! Most teenagers don't drink, over half of teenagers (65%) have never had a full serve of alcohol and only 5% drink on a weekly basis. Most teenagers don't use drugs. Over 80% of teenagers have never used an illicit substance.

Drugs, Alcohol and Bleeding Disorders

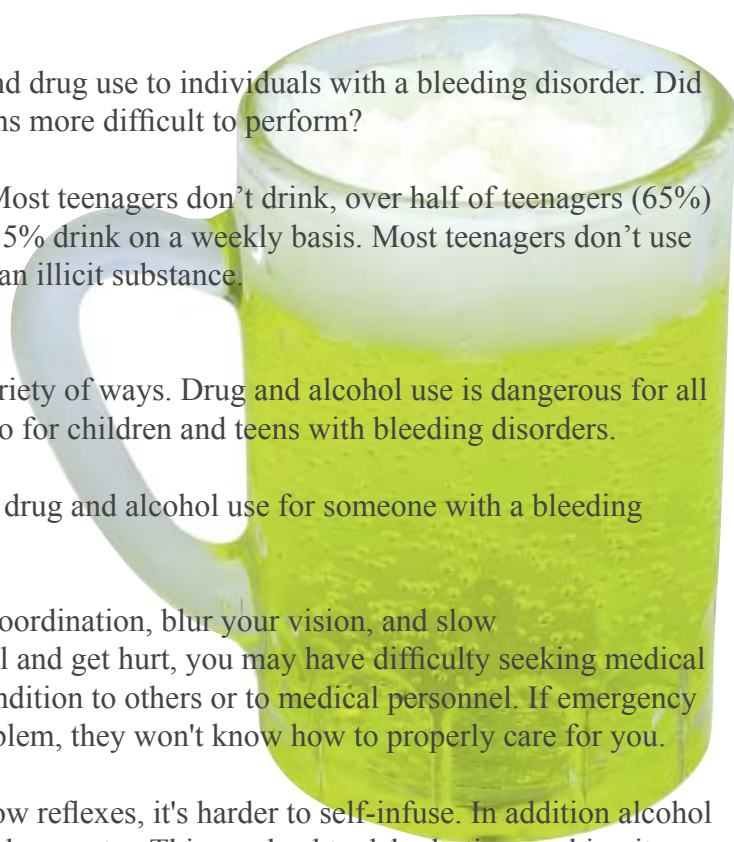
Alcohol and other drugs affect the body in a variety of ways. Drug and alcohol use is dangerous for all children and teenagers, but can often be more so for children and teens with bleeding disorders.

Here are some of the negative consequences of drug and alcohol use for someone with a bleeding disorder:

- Drugs and alcohol can impair judgment and coordination, blur your vision, and slow reaction time. If you take drugs or drink alcohol and get hurt, you may have difficulty seeking medical attention or may not be able to explain your condition to others or to medical personnel. If emergency room staff don't know about your bleeding problem, they won't know how to properly care for you.
- When someone is less coordinated and has slow reflexes, it's harder to self-infuse. In addition alcohol is a diuretic, which means it causes the body to lose water. This can lead to dehydration, making it more difficult to see and find a vein to self-infuse.
- Alcohol acts as a blood thinner in a similar affect to aspirin, even moderate amounts of it can affect blood clotting.

What everyone should know about drug and alcohol use:

- Using excessive amounts of drugs and alcohol can put you in danger. This can include injury, either from loss of balance or consciousness.




© Dana Rothstein | Dreamstime Stock Photos

- Being drunk or high can weaken inhibitions and judgment and can lead to risky behaviour, like fighting and dangerous stunts.
- Drinking and driving is a crime and is very dangerous, it could lead to you ending up in a car accident, which can greatly increase your risk of injury and severe bleeding.

Many interactions between drugs, including prescribed medications are unknown and can be harmful and even life threatening. However we do know that;

- Alcohol is a depressant drug and can intensify feelings of depression or suicide.
- Excessive use of alcohol can damage the liver. If a person has a virus, such as hepatitis C and is taking antiretroviral drugs, drinking alcohol increases the risk of severe liver damage.
- Many drugs and alcohol can be addictive. Kicking any habit is hard, but adding addiction to that habit makes quitting very difficult. If you find yourself addicted to drugs or alcohol and want to stop, there are programs available to help.
- Taking some drugs (including tobacco and alcohol) by swallowing them can irritate the stomach lining and cause cancer and other health problems.

Paraphrased and edited by Graham Norton - Haemophilia Foundation Queensland Manager, from an article supplied by the Drug & Alcohol Coordination Unit of the Queensland Police Service



IN THE Loop
Workshops for people who support people living with HIV


In the Loop is a free workshop for carers, partners, friends and families of people living with HIV (PLHIV).


It is recognised that people who look after, or are close to PLHIV may often feel silenced by the virus and this can make it harder for them to access support for themselves. This therapeutic workshop aims to provide information about support services available in the community and seeks to explore the constraints that carers may experience and how they might overcome these.

The workshop runs twice a year.

For more information about *In the Loop* contact Living Positive Victoria:

TELEPHONE: 9863 8733
EMAIL: intheloop@livingpositivevictoria.org.au
livingpositivevictoria.org.au/programs/in-the-loop

 VICTORIAN AIDS COUNCIL
WORKING TOGETHER

 living positive victoria

WOMEN AFFECTED BY BLEEDING DISORDERS

There are many women affected by bleeding disorders in our community. We may be mothers of an affected child, daughter of, sibling of, grandparent of, and/or have a bleeding disorder ourselves.

Personally, I can tick off four of the above. My name is Sharron Inglis, and I am a symptomatic carrier of Haemophilia A (more recently known as having Mild Haemophilia). My dad has Moderate Haemophilia, and my eldest son Ben is the same. My sister has the same status as myself. I have 2 other children that are not affected.

My parents knew about Dad's haemophilia and, not knowing then what they know now, were told we wouldn't have clotting issues if we were carriers. This was proven to be incorrect when I was 4. So I have been aware that advocating for myself in the medical community all my life has been of utmost importance.

This makes me very passionate about the care of women affected by bleeding disorders, in whatever way that may be. Our children and their care are so important in our lives. Their care can take up a lot of our time and energy (we wouldn't have it any other way!). I understand this. But we must look after ourselves for the sake of our families and for the health of ourselves. We would frown at them if they neglected their health. So when Ben's care moved on to The Alfred, my care for my own issues just continued on as normal.

So, one of my main aims as a committee member with women's care is to make women aware of their own health needs. Let's be realistic: At some stage most of us will need a hysterectomy or hip replacement etc as we get older (ugh!) Let's have a plan in place so the treating doctor knows our clotting status, and the treating Haematologist to contact. After all, do we ever go anywhere without that informa-

tion for our children?

After attending the World Congress my understanding of women suffering with bleeding disorders has expanded. There are many women affected beyond the traditional carriers and I want HFV to represent these women and to create a space for women in a community that is traditionally dominated by men and their condition.

However to do this we need to know the needs of other women and we are keen to hear your story. If you have time please join me in looking at the best way to continue the great work of HFV, but also look at supporting women in our unique community, however they are affected by bleeding disorders.

Current funding of HFV and its core business is focused on specific needs of our haemophilia community and we would like to expand the outlook of HFV but need to look at seeking additional funding to do this. Our hope is to bring together women of similar goals and hope that we can support all members of our community with diverse funding for such a diverse community.

Please feel free to contact HFV if you have any issues you want us to cover or if you would like to personally talk to a committee member. We would love to hear your story, either on a one to one basis, or maybe in the form of a little blurb for our magazine. Maybe you can reach someone else out there that is as unique as you. All our stories are slightly different, but we are all here for you!

With thanks,

Sharron
HFV Committee Member

HEP C NEWS

An update from HFA (Sept 2014)

HFA welcomes the recommendation of the PBAC to add simeprevir (Olysio™) to the Pharmaceutical Benefits Scheme (PBS) for the treatment of genotype 1 chronic hepatitis C.

However, we were disappointed to see that the PBAC rejected sofosbuvir (Sovaldi™) for the treatment of genotypes 1 to 6 chronic hepatitis C on the basis of its high cost and limited information about cost-effectiveness.

Listing these new hepatitis C drugs on the PBS would mean the cost is subsidised by the Australian Government. The PBAC is the government Advisory Committee for the PBS.

Both drugs have already been approved by the Therapeutic Goods Administration for use in Australia. But without subsidies they are out of reach for most people with bleeding disorders and hepatitis C.

You may recall that HFA surveyed community members on these new treatments and made a submission to PBAC with their answers about the potential impact of these drugs on people with bleeding disorders and hepatitis C.

About sofosbuvir and simeprevir

Sofosbuvir and simeprevir are part of the new wave of direct acting anti-viral (DAA) hepatitis C drugs. In clinical trials they had very high success rates, few side-effects, and shorter treatment courses (eg, 12 or 24 weeks). They need to be taken in combination with other medications (eg, interferon, ribavirin, ledipasvir) to be effective. Professor Ed Gane from New Zealand explained more about these new DAAs at a recent conference in Brisbane – tinyurl.com/new-hep-c-treatments.

How safe and effective are these new treatments for people with bleeding disorders? Sofosbuvir has had encouraging results - in a small study in of people with bleeding disorders in New Zealand, it has been shown to be both safe and highly effective when it was combined with ribavirin and ledipasvir, including for people who have previously had unsuccessful treatment.

Next steps

Advancing liver disease and limited treatment options is a real problem for some of our community members with hepatitis C. Treatment that can cure their hepatitis C is a high priority.

HFA will be following up with more representation to government on these new treatments. The first step is to arm ourselves with some more detailed information about the potential benefits of these treatments for our community members in particular, and we will speak to hepatitis specialists about this. We have also asked the Australian Haemophilia Centre Directors' Organisation (AHCDO) for their advice and help with understanding the situation for people with bleeding disorders and hepatitis C nationally. This involves clarifying the data and producing a report that does not identify individuals but gives solid evidence of the reality for our community members.

References

1 Kulkarni, R, Mauser-Bunschoten, EP, Stedman, C, Street, A. Medical co-morbidities and practice. Haemophilia 2014;20(Suppl. 4):130-136.

In memory of
those we have
lost in our
community

Our committee would like
to acknowledge all those we
have lost in our community
since HFV was founded in
1954.

There are many.

We are aware that families
may still be grieving for
their loved ones.

You are not alone.

We hope to be able to
connect families who have
had similar experiences with
loss and offer peer support

If you would like to help
please contact us.

Counselling is available
through your GP.

Other services are also
available such as The Com-
passionate Friends Victoria
[www.compassionatefriends-
victoria.org.au](http://www.compassionatefriends-victoria.org.au)
or Beyond Blue
www.beyondblue.org.au

PARENTS

Do you have a daughter with a bleeding disorder aged 13-25 years?

HFA is currently developing new information resources for young women with bleeding disorders. These resources are for young women aged **13-25 years**.

As part of the development and evaluation process, HFA is looking for parents who have a daughter aged 13-25 years to help share ideas about content that they believe would be beneficial.

These resources are being developed in addition to the women's booklets.

If you are an Australian parent with a daughter aged 13-25 years, HFA would love to hear your ideas about topics and how it will be displayed. It will only require a small amount of your time to answer a survey and when you finish you will go into the draw to win an iTunes voucher!

All it takes is an email to Hannah Opeskin (Health Promotion Officer) to register your interest. E: Hopeskin@haemophilia.org.au

YOUNG WOMEN

Do you have a bleeding disorder?

Are you aged between 13-30 years?

Do you carry the gene – or think you might carry the gene - for a bleeding disorder?

HFA IS LOOKING FOR YOU!

HFA is currently developing new information resources for young women with bleeding disorders. These resources are for young women aged **13-25 years**.

HFA is looking for young women aged **under 30 years** with a bleeding disorder to help share their ideas about topics and what the resource should look like. (If you are aged 25-30 we want to hear your thoughts and ideas about information you wanted when you were younger!)

It will only require a small amount of your time to answer a survey and when you finish you will go into the draw to win an iTunes voucher!

All it takes is an email to Hannah Opeskin (Health Promotion Officer) to register your interest. E: Hopeskin@haemophilia.org.au



The new era for haemophilia treatment — focusing on the patient

**Albert Farrugia lives in Montmorency, Victoria. He is an international consultant on biotherapies and is an adjunct professor at the University of Western Australia and the ANU. Between 2000 and 2008 he served on the Medical Advisory Board of the World Federation of Haemophilia and wrote the WFH's "Guide for the Assessment of Clotting Factor Concentrates" (available on <http://www1.wfh.org/publication/files/pdf-1271.pdf>). Albert has haemophilia B.*

I was recently at a conference where I heard a talk in which the speaker kicked off by stating 'This is a good time for patients with haemophilia.' Of course the speaker did not have haemophilia himself, and I felt like suggesting to him that he should try it and see how good a time he can have! However, it is the case that the therapeutic landscape for haemophilia continues to improve, in Australia and in similar countries. It would be appropriate to reflect how this has progressed over the past ten years or so.

Up to 2004, the sole product available for all Australians with haemophilia A was a plasma-derived concentrate of intermediate purity manufactured domestically. The Australian Government's then policy of sourcing plasma products entirely from domestic blood and manufactures, designated as 'self-sufficiency', resulted in insufficient amounts of factor VIII to cover the needs of patients to what the international norms were in 2004. Concurrently, the availability of recombinant product was restricted to a small number of patients. Hence, in 2004, Australia's per capita usage of factor VIII was, considering its status as a wealthy country, relatively modest and this was reflected in patient well-being.

All this changed rapidly after 2004, in which year the Government allowed treatment of choice to carers and patients. This led to a huge increase in the usage of factor VIII as the importation of recombinant products was not impacted by the self-sufficiency policy. This policy was itself jettisoned in 2006 when the US Free Trade Agreement required its removal. Concurrently, the establishment of efficient, centralised processes for approving haemophilia therapies by tender through the National Blood Authority greatly facilitated access to care for our community, delivered through our network of Haemophilia Treatment Centres.

Which brings us to today. In 2014, Australia uses around 7 international units of Factor VIII per capita, which international research suggests is actually the level of usage reflective of optimal care according to current products.

But we know that many countries, including Sweden, Germany and Ireland, are using more than these amounts.

Why is this?

As our knowledge about haemophilia increases, so does our capacity to deliver better care. The promise of recombinant products lies not just in their safety from transmitting infection, which is no longer a significant risk for plasma-derived products, but also because they represent theoretically infinite amounts of factor. In countries where access continues to improve, the use of higher doses and better prophylaxis protocols is increasing usage but also improving outcomes. Sweden, which has the highest per capita usage of factor VIII, also has the best outcomes in minimising joint bleeds and preserving function. In addition, we know that even the current best prophylaxis regimens do not stop bleeding, and that patient factor levels of 15-20 % are needed for this.

But we also know that all patients are different. We do not understand why nearly 10 % of severe haemophilia A patients hardly ever bleed. There are many indicators which show us that, in haemophilia treatment, one size does not fit all. As we enter into an era of new products, characterised by synthetic molecules which alter properties such as half-life, it is crucial that each patient is characterized as the individual he is, and treatment is adjusted according to those characteristics. In this way, the precious resource which constitutes haemophilia products provided by the community is best used. Naturally, for this personalisation of haemophilia care, the continued strengthening of the haemophilia treatment centres is essential. There are parts of the world where HTC's are under threat, as funders consider that the provision of expensive products which can be self-administered is enough. This is a mistaken philosophy which will result in poor treatment, wastage and increased costs.

We have come a long way in treating haemophilia. But progress is still under way. The future beckons...brightly.

Albert Farrugia

John Stuart Pharo

26th August 1933 - 13th August 2014

Sadly, John Pharo, an active member of our committee for many years recently passed away. John had undergone an extensive surgery in 2012 and had suffered complications. He made a slow recovery but was well enough to attend our Men's Retreat in 2014 and then the World Haemophilia Congress in May. We were all delighted to spend quality time with John at the congress.

There were a number of staff and committee at John's funeral. It really was a celebration of John's life and a send off John would have been proud of. We learnt so much about John from the eulogy his daughter Elizabeth gave. Elizabeth has kindly allowed HFV to publish her eulogy in Missing Factor.

Our dad was a kind, gentle, considerate and passionate man of the world who loved his family and friends. He enjoyed the simple pleasures of life, was an eternal optimist and touched the lives of everyone he met.

Dad was born in Gardenvale in 1933 to Charlie and Agnes Pharo and 5 years later welcomed his siblings the twins Ian and Barbara. He grew up in Hampton attending Sandringham East Primary School. The family spent two years in Bendigo but returned to Hampton after Dad was awarded a Scholarship to Melbourne High. He wanted to be a pharmacist, but an English teacher kindled his interest in literature so he completed an Arts degree with Honours at Melbourne University and took up teaching.

In 1960, he set off with his brother Ian on a five and a half week sea voyage to the UK. He got a job at Selfridges Department Store in London. While working in London Dad shared a flat in Chiswick with Ian, Ron Cashin and future brother-in-law Eddie Price and proudly proclaimed himself as "Lord P (Pharo) of Chiswick". The flatmates worked hard during the week and spent their weekends exploring the UK in Ian and John's little green VW Beetle - often cramming 6 people in the car. They also had some terrific trips to Europe when Barbara arrived. Wine was cheap, the food was good and there were plenty of adventures to be had.

Dad won a Scholarship to study a Master of Arts at London University and fell in love with our mother, Susan Golby who was a nurse. Mum's sister Jane recalls Dad meeting the Golbys for the first time in Weymouth. He turned up in a huge pair of boots, an overcoat down to his ankles and swathed in scarves as if he was going on an expedition to the North Pole! - Dad always felt the cold!

In 1963 Mum and Dad emigrated to Canada and mar-

ried in British Columbia, but had to return to Weymouth 2 years later when mum was diagnosed with lupus.

In 1967 our parents moved to Melbourne where Dad got a job at Melbourne Grammar School. He loved teaching there and always spoke highly of his colleagues.

Helen, David and I had a very happy home growing up with mum and dad always doing their very best for us including providing us all with a good education. We had some wonderful family holidays to Mt. Buffalo, Wilson's Promontory, Sandy Point, Cape Pater-son, Adelaide and the UK. We also spent time at Dad's bush block at Cockatoo, playing hide and seek in old abandoned buses nearby and fending off Kookaburras that would swoop down and pinch sausages off the campfire.

However, life was not without struggles. Mum was diagnosed with skin cancer in 1978 and was hospitalised many times over the next 9 years. It was very stressful for Dad but he maintained a stable household and was a real strength to us all.

Gardening, reading, painting, classical music, golf and attending Lodge gave him great pleasure and helped him to relax. He grew grapes, plums and figs to make wine and jams and grew vegetables - tomatoes and beans were his favourites, but they required a trellis. Like his father Charlie, he made do with what he had and so would cobble together a trellis of bits and pieces of old TV antennas, ironing boards legs, old bits of clothesline and wood - functional but not pretty! That was Dad!

Our English relatives called him "the absent-minded Professor" - he was late for everything. Mum's parents came out to visit us and mum had planned a splendid

dinner for their last evening here. They waited patiently for Dad to arrive home. Eventually they ate their meal and Mum drove her parents to the ship. On arrival Dad turned up clutching a book that he had bought especially for them. He had started to read the book himself, got on the wrong train and was transported miles from home before he realised his mistake.

After retiring from Melbourne Grammar in 1993, Dad was never bored. He worked part-time with his brother Ian who was a builder, his nephew Brad and Rob and Greg. He enjoyed their company, the laughs and the black billy tea and sticky buns or fruit cake at morning and afternoon tea time.

Dad was extremely generous with his time, always putting the needs of others before his own - taking his mother shopping, helping neighbours and friends and donating his time to the Red Cross and the Haemophilia Foundation of Victoria. St.David's church was also a big part of his life and he spent many years singing in the choir and running the White Elephant stall at the church fete. Unfortunately, he like me, was a hoarder and so he always came home with more junk than what he left with!

During his retirement he travelled extensively - including Europe, the UK and Canada. He was very down-to-earth and loved chatting to people and so would always stay in youth hostels. He even mastered building stone walls while helping his sister-in-law convert a French piggery into a holiday house. He also had wonderful trips to New Zealand with Ian and Jill, Barbara and Ed Price and his cousin and life-long friend Cathryn Sinclair.



Dad and Cathryn travelled Australia together, both had a bad sense of direction and so got lost many times - but enjoyed themselves all the same. Cathryn told me a funny story from when they were staying in an old pub in Kalgoorlie in 1999. Dad was having an afternoon nap. Cathryn she smelt smoke and heard a fire engine go by ... the burning smell got worse. A bit of investigation revealed Dad's underpants smouldering away on top of a lamp shade - he'd thought it was the perfect drier and even had the cheek to ask Cathryn whether she could mend the big hole burnt in them!

Speaking of smoking - it was one habit we tolerated. He never smoked in the house and so would always sneak out after dinner under the guise of "emptying the compost bin". We knew that he was having a cigarette and poor Dad, we teased him so much so that he always tried to hide it!

Family was the most important part of Dad's life and so he was overjoyed when Helen and Adam married in 2006. A year later he was thrilled by the birth of twin boys Zachary and Miles. Dad doted on them - they made him feel young again. He took great pleasure reading to them, teaching them how to play cards, chess and checkers, playing hide and seek, taking them to the park, for train rides and playing with them - it was not unusual to see Dad and the twins playing together on the trampoline or up the top of the cubby house having a snack or reading books together.

After his life-saving triple A repair operation in 2012, Dad had his share of ups and downs, but never complained - even though he lost his ability to swallow. Fortunately, last November he regained his swallowing just in time for Christmas. He was thrilled as he could go out for meals and socialise with all his friends again. In January this year he had a terrific time when Barbara and Eddie visited from Canada. He also looked forward to David's trips home from Queensland when they would go to see a play or movie. Dad went away for a men's weekend with Haemophilia Victoria and then attended the World Haemophilia Congress in Melbourne in May - he even caught the train and tram to the Convention Centre. He was his old self again.

Alas it was not to be - life can be very unpredictable. Dad was a pillar in our lives - ever-present, always strong, cheerful, kind, humorous, loving and generous. We will all miss him terribly, but he will live on through us, his grand-children and the lives of others he has touched.

We love you Dad.

AIDS CONFERENCE 2014

**BILL CLINTON ADDRESSES THE DELEGATES:
BREAKING RELIGIOUS TABOOS, THE INJUSTICES OF HIV AND TACKLING STIGMA
AND DISCRIMINATION**



Wednesday July 22, 2014 - Former US President Bill Clinton has told delegates at AIDS 2014, the 20th International AIDS Conference, that finding more economically efficient ways to respond to HIV is vital to saving lives and preventing the spread of the virus.

Mr Clinton, who advocates globally for health security through the Clinton Health Access Initiative (CHAI), made the comments at the conference in Melbourne today as he reflected on the progress made so far in overcoming the HIV epidemic, as well as the challenges that lie ahead.

Mr Clinton said meeting global HIV prevention and support targets is possible within the “existing funding envelope”, but only if resources are used more effectively. “The development of super-efficient systems can help us achieve the 90 / 90 / 90 goals,” Mr Clinton said, referring to the UNAIDS 2020 targets of 90% of people with HIV knowing their status, 90% of people with HIV receiving antiretroviral treatment and 90% of people on treatment having an undetectable viral load.

Mr Clinton said one of the biggest challenges is delivering care to patients in a better way in rural and remote areas.

“How can we reduce the distance they travel to the clinics, the time they wait, the money they spend? How can we launch programs to ensure they feel

supported in their communities without the stigma that makes people still, after all these years, drop out of care,” Mr Clinton said.

Mr Clinton said ending mother to child transmission of HIV, and supporting children with HIV is another challenge – as well as a tremendous opportunity for sustaining progress in the response to HIV. “Almost 50% of all new paediatric infections occur during the breast feeding period. So keeping these women in care until the end of the breast-feeding period is the single most important thing we can do to achieve an AIDS-free generation.”

Mr Clinton indicated that the AIDS 2014 gathering was more of a movement than a conference, and encouraged delegates and those involved with HIV around the world to step up the pace and continue to make in-roads in the global response to HIV. He also paid his respects to the victims of MH17 including the six delegates due to attend AIDS 2014. He said the delegates who died, through their work for the global HIV response “gave their entire lives to the proposition that our common humanity matters a hell of a lot more than our differences.”

Official Press Release

http://www.aids2014.org/WebContent/File/AIDS2014_day4_release_230714.pdf

Dear Community,

HFV is celebrating a big year with our AGM on Sunday 9th November at our family Christmas Picnic.

Hopefully many families will come and enjoy some fun in the sun and take the opportunity to meet others from our community with stories to share.

AGM's are an important part of our annual calendar. The Committee of Management (COM) is re-elected and it is a time to bring new faces in to the important conversations that need to happen in planning for the future. A few long serving members have indicated they will not be renominating and will leave big gaps to be filled. Other members are stepping back out of executive roles and again creating gaps to be filled.

The climate we are in is one of uncertainty as many community organisations are struggling to find their place in recommissioning of services and shuffling of funding by government. HFV is strong with amazing staff and has had a very dedicated COM. However it is a time to stay focused and keep planning for the future for our families and members as well as to continue to work alongside key stakeholders to ensure HFV remains an important voice for people with bleeding disorders. HFV would love to speak to any members that would like to become involved with the COM or any subcommittees as we make those plans to move forward.

After the once in a life time privilege of having a World Congress in our backyard earlier this year, HFV is keen to strengthen and grow but can't do so without support from our community. The COM would love to hear from people living with a variety of bleeding disorders such as VWB and other health issues to ensure your voice is heard in a supportive and productive way.

If you would like to discuss ways you can assist HFV please contact the office and one of the COM would be very happy to have a chat.

Hope to see you at the AGM/Picnic, Family Camp or just drop in for a cuppa.

Regards,

Leonie Demos

On behalf of COM

WFH World Congress 2014

Poster Sessions are now available to view online

There are many different topics covered in these poster presentations including:

- Ageing
- Co-morbidities
- Dental Issues
- Haemophilia Programs
- Musculoskeletal-orthopedic Issues
- Paediatric Issues
- Physiological and Social Issues
- Women and Bleeding Disorders
- Youth and leadership issues



Please go to www.postersessiononline.eu/pr/aula_poster.asp

LADIES DAY 2014

10 Year Anniversary!!!

This year marked 10 years since we started Girl's Day Out and we celebrated in style with Thai massage and Cuban food. True Thai Massage in Prahran really looked after us with wonderful massages while those of us waiting our turn could chat and catch up and enjoy some nibblies. We then moved the chit chat over to Coco Cubano for lunch and a lay-back Cuban experience.

Looking back over our 10 years, I'm proud that we've managed to do something different every year. We started out in 2005 with a lunch in Albert Park during the year before the start of our annual "Day Out" as we know it today in October at Brighton Day Spa. The following year we did a tour of Como House with yoga & massage, 2007 had us "beating" our stress on African Drums, pizza and "3 Minute Angels massage", in 2008 we enjoyed a Chocolate Tour of the city & mini massages and 2009 saw us having High Tea at Woodman's Estate Mornington. A Pottery workshop, (who could forget the infamous fish), & Lebanese lunch followed in 2010. The next year we classed it up with lunch on the Colonial Tramcar Restaurant. We hit the High Seas for a High Tea in 2012 cruising around the Docklands and last year saw us all run away and join the Women's Circus.

As you can see, we've had way too much fun. Some ladies have been there from the start with others joining in along the way as they have found themselves part of the haemophilia family.

All ladies who are affected by bleeding disorders in any way, be it themselves, mothers, partners, sisters, aunts, grandmothers, carers, (or anyone I've forgotten), are welcome to come along, we'd love to meet you. We're a pretty friendly group made up of lots of different ages and circumstances, but we all have a common bond. It's a once a year day out to recharge the batteries. You might be surprised at how much you enjoy yourself once you get there. So keep a look out in the newsletter for next October's event and if you would like any more information or are a bit apprehensive about coming along for the first time, let Julia or Andrea at the office know and they'll help you out.

On a personal note I'd like to thank HFV for the support they've given me in organising this day. They've been right on board no matter what crazy idea I've come up with. But most of all I'd like to thank the ladies themselves who've come along and been such good sports every year regardless of what I've thrown at you. The camaraderie and support you show each other is amazing and what this day is all about.

See you in October

Julie Boal



Our staff and committee would like to acknowledge Julie Boal for all the work she has put into organising these annual ladies day outings for the last 10 years. Julie takes time to really think about activities that will engage, sometimes challenge but ultimately connect the ladies in our community — the mothers, grandmothers, sisters and partners and of course ladies with bleeding disorders too.

We are blessed to have Julie in our community. She is a wonderful role model. Julie understands the importance of peer support. She is open and respectful, engages with others and is willing to go that extra mile.



Thank you Julie for your years of service to HFV - we very much appreciate all that you do.

The HFV Team

2015 HFV FAMILY CAMP

HAEMOPHILIA FOUNDATION VICTORIA INC

WHERE: Forrest Edge, Neerim South
WHEN: 27th - 29th March 2015
WHY: Meet other families affected by bleeding disorders
WHO: All family members who would like to attend, young and old! ALL INVITED

- Heaps of fun activities, meet new people; catch up with old friends, share stories
- Discover new ways to care for yourself and your family
- Relax and unwind... 'Time out' socialising sessions, plenty of games
- All meals supplied from Friday evening dinner to Sunday lunch
- Comfortable accommodation (private rooms with bunk beds) with shared bathroom facilities

SUBSIDISED CAMP FEES TO CURRENT HFV MEMBERS: \$150 per family, \$80 per extra single adult over 18 yrs

Please complete the included form or contact HFV on 9555 7595 for more details.

HOPE TO SEE YOU THERE!

**NOT BOOKED
IN FOR OUR
NOVEMBER CAMP?**

Not to worry!
We have another
awesome camp in
March 2015!

Booking forms will
be mailed with the
February edition of
Missing Factor.

Booking through our
website will be
available soon.

PUT THE DATES IN YOUR DIARY!



Haemophilia Foundation Victoria has just signed on to be part of the Quickbeds Grassroots Fundraising Program. This is a great opportunity for our organisation to raise funds.

IT'S VERY SIMPLE:

Next time you are booking accommodation, go to Quickbeds, use our unique Grassroots Code: 1215 and you'll be helping our organisation.

That's \$10 for bookings up to \$349.

And \$25 for bookings from \$350 to \$699.

And \$50 for bookings of \$700 or more

HOW TO DO IT:

- Go to www.quickbeds.com/?grassrootscode=1215
- Find the hotel you want
- Book it
- That's all

Quickbeds is an accommodation search and booking website owned by the Flight Centre Travel Group.

1. Price Beat Guarantee - if you find a cheaper price we'll beat it
2. Huge range of hotels, apartments, resorts and B&B's in Australia and New Zealand
3. 24/7 Customer Support from an Australian telephone support centre
4. No Fees - no booking fees, no credit card fees
5. Raise Funds for Haemophilia Foundation Victoria with every booking

www.quickbeds.com/?grassrootscode=1215

TELL YOUR FRIENDS: You don't have to be a member to use the club code. Forward this to your friends and family. If they click on the link and book the money goes to HFV!





The Make a Move campaign, which aims to raise \$1 for every person who lives with a painful and debilitating musculoskeletal condition, was announced with a new community service announcement and website where people can sign an online petition.

In addition to raising much needed funds, the Make a Move campaign is raising awareness about the havoc MSK conditions can cause in the lives of those who live in chronic pain.

“It seems easy for politicians to dismiss this huge segment of our society. The 1.5 million Victorians with a MSK condition are not just a statistic, they are 1.5 million people living with chronic pain. It is their pain that governments are ignoring,” CEO Linda Martin said.

“We receive less than 1 per cent of recurrent funding from the State Government. This level of funding sends a clear message to the people we represent. A message that says they are not worth it. Well we are here to ensure their voices are heard. We want them to know they are worth it.”

The Make a Move campaign was launched recently by George Donikian at Federation Square with a live performance by Vicky O’Keefe (the daughter of Johnny O’Keefe whose 1963 hit ‘Move Baby Move’ features on the community service announcement), Wilbur Wilde and the Retro Bandits.

“We were fortunate to enlist the help of many award winning supporters from the film, TV and music world in the creation of Make a Move,” said Ms Martin.

“We hope this fun, positive message will encour-

age the millions of people who live in chronic pain to add their voice to our campaign for change.”

And it’s not just a condition that affects older people. MSK conditions effect more people than any other national health priority area and more than half of those affected are in their prime working age – 25 to 64 years old.

“\$1 for every person with a MSK condition may not sound like much but it would go a long way towards improving the lives of millions,” Ms Martin said.

The public can support the campaign by signing the online petition and donating at www.makeamove.org.au.

About Arthritis & Osteoporosis Victoria

Arthritis and Osteoporosis Victoria is one of the largest musculoskeletal not-for-profit organisations in Australia representing people who live with arthritis, osteoporosis and over 150 other musculoskeletal (MSK) conditions. Currently there are 6.1 million Australians (1.5 million Victorians) living with painful MSK conditions, which in 2012, cost the Australian economy \$55.1 billion. And there’s no cure! We receive less than 1% of recurrent revenue from government funding and rely on the generosity and support of our donors to provide essential services, advocacy, information, education and research.

www.makeamove.org.au



World AIDS Day is held on 1 December each year. It raises awareness across the world and in the community about the issues surrounding HIV and AIDS. It is a day for people to show their support for people living with HIV and to commemorate people who have died.

The global World AIDS Day theme for this year continues on from last year's theme: Getting to Zero: Zero new HIV infections. Zero discrimination. Zero AIDS related deaths.

The aim of World AIDS Day is to encourage all Australians to be aware of HIV; to take action to reduce the transmission of HIV by promoting safe sex practices; and to ensure that people living with HIV can participate fully in the life of the community, free from stigma and discrimination.

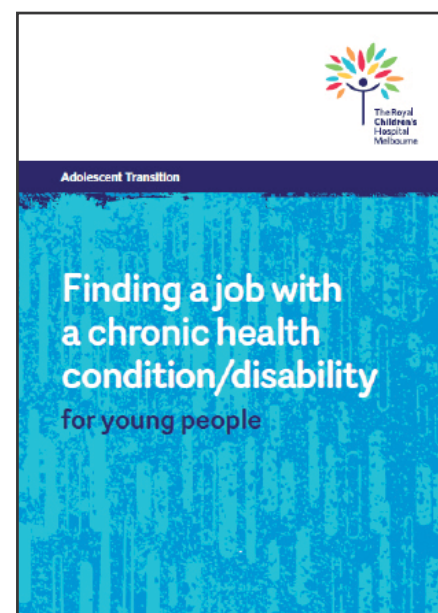
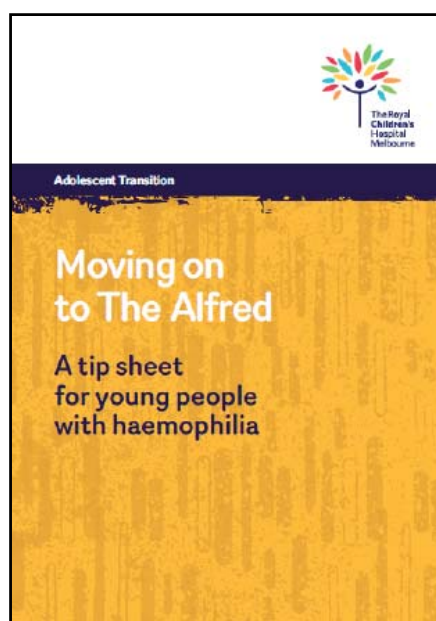
As a community and as individuals, there is a lot we can do in relation to HIV. Working in partnership with people living with HIV, we can encourage others to understand how the virus is transmitted. We can support people to access testing and treatment, as we know that getting treatment at the early stages of infection results in better health outcomes. We can raise awareness that HIV positive people have the right to participate in a community free from stigma and discrimination.

Show your support for people living with HIV on World AIDS Day by wearing a red ribbon, the international symbol of HIV awareness and support.

www.worldaidsday.org.au

Two new publications - developed by the RCH Transition Team

- **Getting to The Alfred**
- **What will be expected of you at the Ronald Sawers Haemophilia Treatment Centre**
- **How your clotting factor deliveries will work**
- **How the Ronald Sawers Alfred Haemophilia clinic runs**
- **What happens at your first appointment**
- **Your rights and responsibilities as an employee**
- **Managing your health at work**
- **Telling your employer about your condition/disability**
- **Preparing for an interview**
- **Professional vs personal life**
- **Other support services**



For more info www.rch.org.au/transition/factsheets_and_tools/Brochures/

ADDRESSING AUSTRALIA'S SKILLS SHORTAGE by telework for people with disabilities

A Canberra start-up is enabling employers to tap into a huge talent pool of Australians living with a disability using telework technology to remove barriers.

Enabled Employment is privately funded and already sourcing employees for clients including the Department of Health, the ACT Department of Health, and Disability ACT, Veritec and Aspen Medical.

“We have many highly qualified people with disabilities who want to work online and from home”, said founder and Chief Executive Officer, Jessica May.

“We use technology to match people with disabilities with employers seeking skilled workers or professional services.”

The idea came from Jessica's own experiences as a worker with a disability. In 2011, Jess suffered with anxiety after the birth of her first child, and was diagnosed with panic disorder. She wanted to return to her full-time job, but was terrified of going into the workplace.

Jess knew that working would help her anxiety, but despite being highly commended and a skilled worker, she could not find work which she could do from home.

Ms May said most people with a disability have sought-after skills and experience but face barriers that stop them working in a conventional workplace. These barriers can be both physical, and social.

“Our one-stop-shop lets them browse for jobs they can do remotely by telework and covers everything from early job hunting to getting paid.”

“Australia has among the lowest disability employment participation rates in the OECD and we intend to change that.”

Enabled Employment started under the Griffin Accelerator Program in July and has already received widespread support. It plans to expand into overseas markets soon.

www.enabledemployment.com



Enabled Employment
Real work. Real jobs. Real people.

Why consumers support doctors on drug rep ban

Consumers' confidence in their doctor relies more than ever on trust that they are being prescribed the right medicine. The Consumers Health Forum supported the launch at the weekend of the No Advertising Please (NAP) campaign in which doctors are pledging not to accept visits by pharmaceutical company representatives for the next year.

The Chief Executive Officer of CHF, Adam Stankevicius, said today the NAP statement cited the evidence from several reputable studies showing that doctors can be influenced to prescribe inappropriately as a result of claims made to them by drug company representatives. "A study of Australian GPs in 2010 found that only about half of presentations from pharmaceutical company sales representatives included information about side effects, drug interactions and contraindications. "The NAP statement also highlights that pharmaceutical manufacturers are paying out billions of dollars in the US for failing to disclose negative safety data concerning aggressively promoted drugs.

"CHF supports the doctor-initiated NAP campaign because it believes it is essential to ensure patients are getting the best available and most appropriate medicine, prescribed by their doctor, free of any influence from drug companies," Mr Stankevicius said.

CHF advocate on medicine safety issues, Alison Marcus, told the NAP launch in Adelaide on Saturday that now, more than ever, consumers' confidence in their doctors must rely on trust: not only that the doctor has the patient's interest foremost in mind, but the medicines prescribed are the most appropriate.

"We know that GPs face unparalleled pressure on their time: caring for patients, keeping a practice going and keeping abreast of medical developments and medical literature," Ms Marcus said.

"At the same time, patients have easier access to medical information, good and bad, thanks to the internet and Dr Google.

"The information avalanche is why the "No Advertising Please" campaign is so important to consumers," Ms Marcus said.

"For doctors to retain their privileged position as the source of much reliable information for individual patients, they must be seen to be free of the possibility of any inducements, however subtle, by the pharmaceu-

tical industry.

"The Consumers Health Forum supports the NAP campaign because of the potential to drive best practice: that is, seeking independent sources of information about medicines and using appropriate clinical guidelines.

"As you will have seen from the NAP information on the website, there is persuasive evidence that risks and harms are not always conveyed to prescribers, and that de-prescribing or no prescribing is unlikely to be presented as an option.

"Many patients are unaware that doctors may receive regular visits from pharmaceutical reps using persuasive techniques, or even the possibility that 'off-label' prescribing may be promoted. This is a significant potential breach of trust in the doctor patient relationship, and calls into question the fundamentals of informed consent when treatment is discussed with a patient. "We know that general practice is no easy gig. Access to our GP is fundamental to good primary care. Clinical practice is demanding for time-stretched practitioners striving to meet patients' needs, often in times of crisis and suffering for patients and their families, all while trying to keep abreast of torrents of information.

"Perhaps in the past these reps' visits were perceived as being for the doctor's benefit, when clinical information was harder to access. This is no longer the case, and in fact it is now both necessary and possible to be selective about information sources," Ms Marcus said. Mr Stankevicius said the issue of drug company perks to doctors and the disclosure of them, had been a matter of disagreement between CHF and Medicines Australia for a significant period of time.

MA's industry group rejected both the advice of its own Transparency Working Group and CHF's suggestions for more rigorous disclosure provisions than proposed by MA.

"CHF has been an independent advocate for transparency and accountability in healthcare for over 25 years and we have raised the issue repeatedly, most recently through our submission to the ACCC on MA's own Code of Conduct," Mr Stankevicius said.

PRESS RELEASE, October 12th 2014



HFV Family and Friends Christmas Picnic (BYO) SUNDAY 9th NOVEMBER

FACE PAINTING
& BALLOONS

10.30am -2pm Bicentennial Park, Scotch Parade, Chelsea

- two big mound slides
- Smurf village with a music hut, story hut and play hut
- Liberty Swing for people with mobility difficulties
- sculptural gardens
- a shaded sand pit
- Tinkerbelle sand pit
- a giant basket swing
- huge green grasshopper and bee springers
- stand-on spinners
- rope climbing frame
- tic-tac-toe
- monkey bars
- flying fox

AND HEAPS MORE!!!



Shelters with BBQs and tables
and the area is surrounded by fences with child proof gates.

BOOKINGS ESSENTIAL on 9555 7595 or email andrea@hfv.org.au

GRANDPARENTS & FRIENDS LUNCH

Our HFV Grandparent's Group got together in August at Madelines at Jells. It was lovely to see some new faces and meet up with our regulars. We were able to talk about our unique families and enjoy our time together.

HFV would like to thank Carol Ebert for organising this event. Carol has been convening this group for many years now and is always very careful to chose varied locations that would appeal to the group.

*THANK YOU Carol
— The HFV Team*



our community

THANK YOU!

Our committee and staff would like to say a very big thank you to those in our community that take the time to help raise awareness and funds for our Foundation and HFA. And there are many of you!

Your hard work and dedication to improving the lives of others in our community is greatly appreciated.

The Horkings family recently participated in the Run Melbourne challenge and raised over \$800.

There has been much activity during Haemophilia Awareness Week with many families supporting the Red Cake Appeal. Thank you to all those members who got busy baking,

We have a family that organises an annual shopping tour fundraiser and other families involved in bike ride fundraisers. There are kids organising fund raisers at their schools. The Field Family held their annual "Paint the town Red" promotion with the support of many people in their community.

We have a special group of ladies who put together hampers to be raffled off at our events and we have families that donate gift vouchers and other items for our events.

All these wonderful ways to raise awareness is greatly appreciated by all at HFV and the funds raised go to helping support the bleeding disorders community. Thank you.



2014 HFV CHRISTMAS CARDS



Please see enclosed order form for more details
or contact the office on 03 9555 7595

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

CARRIER INFORMATION SESSION

HFV Carrier Information Session
is still a work in progress.

We do hope to have a session
booked for early to mid 2015.

We will keep you posted.

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

BLOOD, SWEAT AND GEARS...

Randall's
Really Big Bike Ride For Haemophilia
5,000 km across Australia



personalchallenge.gofundraise.com.au/page/Randall_Stephens

My name is Randall Stephens, I have a bleeding disorder called Haemophilia. I am undertaking a 5,000 kilometre cycling journey across Australia as a personal, physical, and mental challenge to help raise awareness of Haemophilia and other bleeding disorders. The ride will be an extreme challenge for me. Being a Haemophiliac has meant coping with a great deal of adversity, struggling to overcome the debilitating problems of joint inflammation, deterioration and internal bleeding.

Like many Haemophiliacs, I had to cope with a medically-acquired Hepatitis C, living with this virus for over a decade before undergoing an extreme and prolonged course of medication (Interferon and Ribavirin) in order to clear the virus. I've also encountered blood-treatment problems of my haemophilia, from anti-bodies called inhibitors, which for a time made me extremely vulnerable to spontaneous bruising.

With the support of family, and access to free/affordable medical treatment in urban Australia, I've managed to overcome all of this adversity. Having been freed of Hepatitis C for over nine years now, and working hard with physiotherapists to keep my muscles and joints strong, has allowed me to live an active and fulfilling lifestyle. Working, travelling, cycling and even performing poetry, and a long life expectancy are now a reality for me.

Globally however, 75% of people with Haemophilia and other bleeding disorders do not receive adequate care, or indeed any care at all. Around the world millions of men, women, and children suffer needlessly with pain, stigma and disability and many children do not survive to adulthood.

Funds raised will support people with inherited bleeding disorders in Victoria and in parts of the world where there is little or no treatment. These projects include family camps, peer support weekends for older men, boys education programs and work in developing countries to help the bleeding disorders community build stronger support networks.

You can follow Randalls adventure at www.facebook.com/randallsreallybigbikeride or go to personalchallenge.gofundraise.com.au/page/Randall_Stephens and support a great cause.