

# THE MISSING FACTOR

Check out all our member  
congress session info on  
*your* **FREE HFV USB**



**2014 FAMILY CAMP**  
**22nd & 23rd NOVEMBER**  
**Don't miss out — book now!**

Attending a  
**Haemophilia Camp...**  
*a personal perspective*

**Where to from here?**  
*Capturing the passion of  
Congress and building for  
a strong future at HFV*



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a personal perspective



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## DIARY DATES

Horsham Regional Visit — 10th Aug

Grandparent's Luncheon — 24th Aug

Haemophilia Awareness Week —  
12th to 18th Oct

Ladies' Day Out — 19th Oct

AGM — To be confirmed

2014 Family Camp — 22 & 23rd Nov

## 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

WOW. After four years of planning the WFH congress finally arrived in Melbourne and it was without doubt worth the wait and all the hard work. I am sure I speak for all our Victorian delegates that attended when I say I felt proud to be a Melburnian. Not only was the venue and location perfect, we and our international guests were treated to perfect May weather.

I have been fortunate to have attended a number of international congresses but that does not make the experience any less humbling. As a mother of a young man with haemophilia I see guys of a similar age from other countries facing great challenges with restricted treatment or no treatment and dealing with severe mobility issues. It is a stark reminder of how privileged we are here in Australia.

I wish to say thank you to all our community who attended. It was so nice to get to meet some new members of HFV and to see so many familiar faces from various past HFV events. There were many HFV members dressed in yellow volunteer shirts assisting our global friends.

You will find enclosed in this edition of Missing Factor a HFV USB. This USB contains many reports by our members regarding the congress. We hope you will take the time to read them and benefit from what they learnt and their experiences at the congress.

You will have noticed that included with this edition of Missing Factor is the latest edition of Good Liver. Hepatitis Victoria have kindly supplied our members with a copy of their latest edition Good Liver to help raise awareness of Hep C, Hepatitis Victoria programs and the new treatments available. As you may know World Hepatitis Day was just celebrated on 28th July with the theme Think Again, which is calling on all people, including state and Commonwealth decision-makers, to Think Again about the challenges posed by these epidemics.

As many of you are already aware HFV is primarily funded by the department of health through their Blood Borne Viruses and Sexual Health department. As part of our funding agreement it is essential that HFV complies with the criteria and objectives set out in our Health Promotion Plan with the department of health. This is essentially focussed around BBV, health promotion and prevention.

Thanks to the department of health Andrea and Julia had the great opportunity to also attend the AIDS Conference here in Melbourne. It was a sombre occasion following the deaths of such influential AIDS researchers on the MH17 flight. Researchers whose work has positively impacted the lives of many of our members. The sessions our staff attended covered topics including new treatments for HIV and co-infections.

I am delighted to announce that HFV have managed to obtain funding for a family camp this year! This was somewhat unexpected as we had assigned funds to enable members to attend the congress. Needless to say we are delighted to have this opportunity as many members had voiced their disappointment at the postponement of the annual camp earlier this year.

This camp will be slightly different as it will just be for one night, our HFV committee are running the program with the help of some of our skilled community members. This camp is being run in conjunction with the RCH team who will be running a couple of sessions on the Sunday morning. We really hope this camp will be well supported by our members. We will be resuming our 2 day family camp in 2015 with the date and venue to be confirmed.

Hope to see you in November at the 2014 Family Camp.

Ann Roberts

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.

## Where to from here?

### *Capturing the passion of Congress and building for a strong future at HFV*

After attending a once in a lifetime opportunity to be part of the World Congress in Melbourne in May, like many in our community, the Committee of Management (COM) at HFV has an even higher level of passion and commitment to support those in our community affected by Bleeding Disorders and BBV's in Victoria.

With a diverse community to support and so many areas of need the COM has discussed the best direction to take for future planning at HFV.

The four areas of priority are:

#### Supporting Women in our Community

- Needs of Carriers
- VWD and other bleeding disorders
- Undiagnosed conditions for future members of our community
- Identifying possible new funding opportunities
- Sustainability for a new direction
- Relationship to existing HFV and HFA
- Sisterhood with others - how can we learn from others such as the Canadian Project

#### Future-proofing our community

- How to engage with our youth in planning and conducting future activities?
- Voices from youth – relevance and fortification for times ahead
- Passing the torch – encourage investment in shaping HFV's future
- Responsibility and succession – identifying other possible areas of funding and training in our future

#### Investing in our Community

- Engaging with our diverse Community – working together inclusively and effectively
- What does our community look like?
- Who are our partners and stakeholders?

Are we working together collaboratively?

- Who should we be talking to? Preparing for funding opportunities ahead
- How do we communicate with and hear from our community - Newsletter? Website?

#### The Patient Factor – Encouraging Best Health Care Options for our community

- Treatment plans – trends and challenges
- Compliance and prophylaxis
- HFV relationship with our Health Treatment Centres
- Strategic planning for future funding
- Working together – strength in partnership approach
- Encouraging and supporting others – especially agencies overseas in under-developed countries

However these are all areas that require an enormous amount of work and all equal in importance for our community at HFV.

HFV needs your input to help us make this happen. Every member of our community brings a different perspective to the work of HFV and all opinions are valued by HFV and its COM. Some are under the misunderstanding that unless you are prepared to be part of the committee there is no role for you at HFV. The COM are here to engage with the community and are looking at ways to be more inclusive in our work. Like many of us we are time poor but passion rich so now is the time to offer your time no matter how small to see how you can help HFV.

If you would like to be part of this vision and contribute to HFV please contact Andrea or Julia at the office to discuss. Members of COM are always happy to speak to you and encourage you to contribute to our work. As HFV covers an entire state it is not always practical for members to attend meetings etc. However

with technology the world is increasingly shrinking and with that brings opportunities for everyone to be a part of HFV's future by email or other mediums. The COM is looking at ways to engage with members across our community by sub-committees and discussion groups to try to be inclusive of everyone's needs.

HFV is committed to working in partnership with both external stakeholders but also from within our community. If you are not sure what you have to offer I ask you to consider these questions:

- Have you ever left a medical appointment and felt you were not heard and that your particular needs were not addressed? Do you have an idea about what you might have liked to happen?
- Has your son/brother/father/uncle ever doubted the value of their treatment plan and not followed 'doctor's orders' despite the best intentions of the medical team?
- Have you always wanted to be part of a family camp or activity but been too shy to make the leap?
- Have you ever wished that HFV would run a session on....?
- How do those in the Haemophilia community engage with others with chronic illness?
- Why are the articles in the newsletter always about older people and not what I am interested in?

Your experiences and those of your loved ones around you all contribute to making things better for generations to come. Now is the time to be part of that vision and to take the inspiration of others to help drive HFV to a sustainable and dynamic future. Future funding will always be the biggest risk in our community so working together as effectively as possible is crucial now as always.

Your interest may be in one of these areas or all of them or maybe you have identified something different that HFV should be thinking about?

We welcome you to be part of this conversation at HFV and hope to hear your voice as part of the future planning. Every contribution is valuable no matter how big or small so let us know your thoughts and how you can also make a difference. We are just an email or phone call away so look forward to that conversation.

Leonie Demos  
Executive – Committee of Management

## Reminiscing about WFH World Congress in Melbourne

It's hard to believe, that it has come and gone so quickly. I had the absolute pleasure of being involved in a working capacity at World Congress. I was one of the coordinators for the 85 Volunteers who helped out.

It was so inspiring to see all the different type of people who just want to help in some way, many who were not directly involved in the Haemophilia Community.

As a Carrier of the Haemophilia gene, I felt that I was able to give something to the running of this amazing event that was held in our back yard, so to speak. I met young Mum's who were just getting involved for the first time, and I know that even though it was a huge learning curve for them, they would always look back on this gathering as a stepping stone towards understanding a bit more of the puzzle of Haemophilia.

I met Grandparents who felt that this was a small way that they could help their little ones. I personally had family friends who just wanted to help.

With support like this from our community, how can we not succeed in growing and developing the Australian Haemophilia Community.



By Carol Ebert



## WFH CONGRESS SESSION REPORTS

*The following articles are from HFV members that presented or attended sessions at the WFH. A USB with reports from other members that attended has been enclosed with this magazine for all members. We hope this will enable more members to benefit from those who attended the congress*

### DISCLOSURE:

### WHY AND HOW TO TELL ABOUT YOUR HAEMOPHILIA

There seems to be many reasons why not to disclose to people about your bleeding disorder. I say “reasons” and not “excuses” because whatever thoughts are concerning you about disclosure are usually very valid. I will focus on career and relationship disclosure as they seem to be the two main areas of concern.

As a child and young adult the choice to disclose was not usually mine as my parents thought whoever or whatever I was involved in had to be informed in case of any accidents occurring. This of course was things like school and organised sporting activities.

Now, looking back, I can totally understand why but at the time being “exposed” did have some negative impact. This started in secondary school in the form of verbal bullying mainly because I wasn’t allowed to take part in many of the sporting activities.

My haemophilia was not obvious and most students and even some teachers thought I was faking. The irony there is that I went to that particular school because another haemophiliac was already there. However, he was much more severe and had braces on both of his legs, so that’s what they thought I should have been like. However I didn’t take too long to fit in by using my many charms and good looks to good effect. But there still remained a few who doubted me.

As I moved into adulthood the decisions around disclosure rested with me. My very first job interview loomed so I had to decide whether to disclose or not. I had both ankles and my right elbow as target joints and these were very unpredictable, so there was no doubt I would have a bleed at some point during my career.

My decision was to go in with an “honesty is best” policy. I explained to my boss the ins and outs of my haemophilia, along with the treatment, but also not forgetting to add in my good qualities as well. I did get the job and I was told my honesty had actually made

the difference.

As I’ve changed jobs over the years being open about haemophilia has never been an issue. Having said that I went to work on many occasions with some very painful bleeds and that served the purpose of showing that if I did take a day off then it meant I was really sore and genuinely couldn’t make it to work.

However I did change my honesty policy when I was diagnosed with HIV and Hep C. Back then there was so much hysteria surrounding these viruses that there would be next to no hope of holding or even getting work at all.

This was about the time my wife and I moved interstate and we knew no one. We decided not to disclose anything about the haemophilia and I managed to get through 5 years without anyone being the wiser. I had an elbow frozen at about 90 degrees which was hard to disguise but I explained it off as an accident I had as a child and everyone was happy with that.

When my wife and I moved back to our home town then I was back to having to disclose my haemophilia. Though I was employed by people that didn’t know me the chances of them finding out from someone who did were quite high.



[http://www.dreamstime.com/stockimages\\_info](http://www.dreamstime.com/stockimages_info)

Again being honest about haemophilia wasn't a problem but now the concern was my health was deteriorating because of the blood-borne viruses. Over the course of a few years I had to negotiate reducing working hours, but I blamed my haemophilia (which was partly true).

Luckily I had good employers who valued me and were happy to keep me on. I think if anyone is good enough at what they do then I think a lot of employers would do the same. As I got older my joints began to decline rapidly and it was a combination of health problems that forced me into retirement in my mid-forties.

Moving onto relationship disclosure; now, I can't spend too much time on this as my girlfriends at school all knew about my haemophilia and my wife knew through our common circle of friends and we were already a couple when we found out about the HIV and Hep C.

However I have seen the effects of people in relationships that have hidden things and this can be disastrous when the relationship gets serious. Nobody likes secrets and the fact is the longer you hide a secret, the more difficult it is to talk about and the harder it is to hide. Similarly if you spin a web of lies, you have to remember them and often create more and you can end up in a hell of a deep hole that you may never get out of. It also creates a level of distrust that may be hard to dispel.

*So what advice can I offer on disclosing your haemophilia or blood borne virus?*

First you must identify the situation and how important it is to you. Is it for career or personal reasons? Either way it's a personal decision that, once out there, can potentially, have a significant impact on your life.

As dramatic as that sounds, preparing for possible outcomes can lessen any negative effects that may come your way. So let's explore the scenarios mentioned above.

Career: Firstly you have to identify if you legally have to disclose your disorder. If you've chosen to pursue a career with a health element to it like the Armed Forces or Police Force then you should arm yourself with all the available up to date information on haemophilia plus a personalised letter from your specialist supporting your argument that you believe you can do

that profession. You may even need to get some legal advice.

In other normal low risk careers then it's up to you if you wish to disclose. You know your body and whether you could competently carry out your duties. If you do choose to disclose then give your potential employer some confidence in how well your condition is managed and it should rarely, if ever, inhibit your duties but you just wanted to inform them to be honest with them.

If you decide not to disclose then that's ok too but you really need to be super diligent with your care to minimise time off. Often these day's businesses have team building exercises that may prove a problem for you if it's really physical, so be aware, you may need to treat beforehand.

Relationships are a different ball game. I believe you have to be honest. That doesn't mean to go and blurt out everything on the first date but if you think things could get serious then fess up sooner rather than later. Reassure your partner that haemophilia is just a small part of you and then give them as much information as they ask for, but don't over load them.

At some stage you may want to take them along to see your specialist or social worker. Your partner may even want to have a private meeting too so they can ask questions they might not want to ask you. I think you should support this as this shows you have nothing to hide. You would have to give your doctor or social worker permission though as they have your confidentiality to uphold.

Your haemophilia centre or foundation can be a great help too by providing information booklets on many different topics and are terrific at offering avenues for peer support which can be the most useful of all tools.

To finish, I have found being open and honest about haemophilia and my bbv's has been very positive for me. It's actually opened doors for me and created some opportunities I would never have got otherwise. I've met some great people along the way all the while creating awareness, often inadvertently.

If you view your disorder with a positive attitude then people tend to be positive towards you.

Neil Boal

# Recipes for Healthy Living: Beyond the vegemite sandwich



## How nutrition affects Coagulation.

Joanne Deutsche, Family Nurse Practitioner,  
Oregon Health & Science, Treatment Centre, Uni-  
versity USA.

1. Identify deficiencies,
2. Review some supplements,
3. Obesity,
4. Effectiveness of weight loss strategies.

### Iron:

- Widespread nutritional disorder in the world.
- Child bearing woman, children, elderly most at risk.
- Iron from meat and fish is the best.
- Vitamin C, B12, folate & zinc can facilitate iron absorption.
- Avoid antacids, PPI's or calcium supplements.

### Iron Supplements:

- Ferrous sulfate 65mg elemental iron.
- Ferrous gluconate 35mg elemental iron.

### Ferritin is your bank account:

Haemoglobin – iron containing protein that stores iron in the liver and spleen.

Nearly impossible to keep up with menorrhagia without iron supplements. Low Ferritin levels even without anaemia may be associated with fatigue.

Intravenous forms of iron are safer than ever and may be necessary.

## Vitamin deficiencies

Vitamin C (Ascorbic Acid), need for healthy bone, teeth/cartilage. Needed to make collagen found in blood vessel walls. 90% of Vitamin C in human diet is from fruit/veggies. 90mgs per day for men > 18 years.



75mgs per day for women > 18 years.

Vitamin D Sunshine vitamin. Promotes calcium & phosphorous absorption in the gut. Needed for bone growth & bone remodelling by Osteoblasts/Osteoclasts. Protects older adults.

Vitamin D	Deficiency < 30 mmol/L
Inadequate	< 30 – 50 mmol/L
	Sufficient > /= 50 mmol/L
	Potential adverse > 125 mmol/L.

Vitamin D RDA 600 IU (15 MCG) AGE 1 – 70, >= 70 is 800 IU (20MCGS).

Fortified foods in USA provide most Vitamin D, varies between countries.

D3 is cholecalciferol and synthesized in the skin. Synthesis from skin requires UVB light exposure. Further from the equator, less available required wave lengths. D3 from diet from animal source. D2 (ergocalciferol) from plant sources. Only fish has Vitamin D in it.

Calcium – Diet is the best source, no limit. If supplementation is necessary, not more than 600 mg at once. Peak bone mass depends on adequate levels. If Levels drop PTH stimulates osteoporosis. Found in kale, broccoli, green vegetables. Calcium sapping medications – corticosteroids, etc.

Vitamin K – co-factor in the synthesis of clotting factors II, VII, IX & X. Important for bone health (impairs bone protein osteocalcin). Newborns most at risk.

## Supplements of concern

Vitamin E – Antioxidants protects cells from damaging effects of free radicals, which are molecules that contain an unshared electron. Vitamin E affects dilation of blood vessels, inhibits platelet aggregation. Found in nuts, seeds, vegetable oil and leafy greens.

Is Vitamin E worth the possible risk of bleeding? Have not found any adverse effects from consuming

Vitamin E in food.

Omega 3 – Fatty Acids

DHA, EPA found in fish oil, ALA found in plant seed, chia.

In USA recommend eat oily fish at least twice a week.

**Cardio protective effects, anti-inflammatory effects, antithrombotic effects.**

2.8 million people die worldwide as a result of being overweight.

High income graph shows high overweight. Women are significantly obese all over the world. In USA rates for overweight and obese people affected by haemophilia roughly the same. What do we do – Diet, Surgery?

**Obesity and Haemophilia.**

**Kristy Wittmeiser – Canada.**

Factors affecting joint health in Haemophilia.

Body Mass Index

Physical Activity Level

Obesity associated with hip and knee replacements and with complications. Association with osteoarthritis.

Frequency of bleeding does not differ between men with haemophilia who are obese or non obese.

Systems affected by obesity:

Adults and Youth – musculoskeletal, endocrine, cardiovascular.

Study found 98% job of haemophilia staff is to address overweight or obesity management. Evidence based considerations. Why are we recommending weight loss? Real versus perceived need? Is the individual ready? What will we recommend?

- weight loss vs behaviour change,
- weight loss = energy in < energy out.

Bias or judgement by Health care professionals.

Healthy eating, physical activity, reduced stress, adequate sleep – benefits everyone. Physical activity guidelines > 1 hour per day of moderate to vigorous exercise. Screen time < 2 hours per day, not including homework.

Brazils Food Guide.

Be critical of food industry advertising, introduce healthy eating, teach how to cook from scratch, eat with and sit down with people.

Andrew Selvaggi shared his personal life story on how he lost weight and changed his life dramatically. He is now a personal trainer and consultant.

By Donna Field

## HAEMOPHILIA AWARENESS WEEK 12-18 October 2014

HFA will be running their Red Cup Day promotion for Haemophilia Awareness Week.

HFV have decided to support HFA in their efforts rather than run a separate campaign.

HFV would like to highlight the CRUTCHES FOR VIETNAM appeal that the Alfred HTC team is supporting.

We are delighted that the Field Family have agreed to donate 25% of the funds raised at their annual 'Paint the Town Red' Awareness Week fundraiser to this important cause.

Crutches in Vietnam cost about \$15 per pair. Crutches are crucial in providing mobility for people with bleeds or joint damage in Vietnam.

The Alfred team will be heading to Vietnam in November to support a treating hospital and hope to be able to bring funds for the much needed crutches.

HFV recently pledged \$500 to the appeal on behalf of our members.

If you would like to support this appeal, please forward any money raised to our HFV office.

Many thanks — The HFV Team

## WFH CONGRESS - OUR EXPERIENCE

We are a couple in our seventies. John has mild haemophilia.

In our working lives we were not or, in John's case, rarely involved in conferences, so apart from anything else, in that way, this was a very new experience for us, and at first, involved us in quite a learning curve of finding our way around, registering, and reading the schedule.

The first thing that struck us was the huge number of attendees, from the very large number of countries, and thus, the enormity of the task of organizing the event, which was obviously extremely well done.

The availability of subsidy gave us the opportunity to gain same knowledge of the most recent developments in treatment, and an insight into progress being made in 'closing the gap' between treatment availability for those of us in developed countries and those in under-developed countries.

Highlights of the congress, for us were:

- Exposure to stories of inspiring people's experience in overcoming what haemophilia has thrown at them in life.
- The announcement on the first day by the WFH President Alain Weill of donations of factor by big pharmaceutical companies to the WFH Humanitarian Aid Program. We will not forget in a hurry, the emotion in us and obviously in him, as he held up the first unit produced in a new factor production.
- The first time we walked into the Exhibition Hall, and first we encountered Nuriye Vanggaard, from Switzerland, who told us about the work of Novo Nordisk's Foundation in providing holistic care to people with haemophilia in underdeveloped countries. It was a revelation

to us and very heartening to learn about a pharmaceutical company (so often criticized) using some of their profits in this way.

- Andrew Selvaggi's story of his great turn around from a grossly overweight teenager in a wheelchair, to a healthy personal trainer – inspiring others.
- Meeting Laurie Kelley, the American woman who set up and now heads up the Save One Life organization that we are part of – that enables individuals to help by sponsoring individual people with haemophilia in under-developed countries. We just happened to be near her when someone called her by name. We were able to shake her hand and chat for a few minutes about her work. She knew personally one of the people we sponsor.
- The 'last minute' replacement speaker from Malaysia, a young man from Malaysia, who spoke about the difference between arthritic pain and pain from a bleed. He was a delight to listen to, and an inspiration.

- Reinforcement of advice re exercise and healthy eating.

In general, we were very impressed with the venue for the congress; the catering; the quality of the speakers; and last but not least, we loved our accommodation, and the fact that it was only a short walking distance from the congress venue.

John and Joan Bates



*Sometimes people admitted to hospital are also dealing with other serious concerns. This can include legal issues.*

*Legal issues can cause health problems and health problems can create legal difficulties. So Alfred Health and Maurice Blackburn Lawyers now provide a free legal clinic that will provide advice for patients' health-related legal issues.*

*The **HeLP** Legal Clinic is available at no cost to Alfred patients. It is also available to relatives of patients and others who are close to the patient who believe the patient may have a legal need.*

*"We're dedicated to offering our patients extra help. Not just medical care, but legal help too."*



**PATIENT LEGAL CLINIC**

ALFRED HEALTH +  
MAURICE BLACKBURN

**> What are health related legal issues?**

Breaches of the law may cause or aggravate health problems. For example – domestic and elder violence, child abuse, drug taking, and other injuries. Legal assistance may be needed to address the situation that has caused the health problem. For example – refugee status, homelessness, housing conditions and tenancy, and access to pensions and benefits.

**> Health/disability status may create a range of legal problems**

For example – superannuation and insurance for those who need to cease employment permanently or significant periods, and advanced care directives, enduring powers of attorney, and guardianship for those who are or will be unable to make decisions.

**> How do I make an appointment to see the lawyer?**

Just ask a doctor, nurse, social worker or other person involved in your treatment to make an appointment for you.

**> What happens when I see the lawyer?**

The **HeLP** Legal Clinic lawyer will provide you with advice about what you should do if it turns out that you have a legal problem. Anything said to the lawyer will be covered by legal privilege and remain confidential. Records of the legal clinic cannot be shared with Alfred Hospital staff or anyone else unless you specifically request this. If you have a legal problem the **HeLP** Legal Clinic lawyer will not represent you. You will be referred to a person who is able to help and represent you.

**> I have a complaint about my medical treatment**

The **HeLP** Legal Clinic lawyer does not provide assistance for complaints against Alfred Health or your treatment. If you wish to make a complaint you should first take it up with the health professional concerned. If you are not satisfied you should ask to speak with the Patient Liaison Officer at The Alfred.

**> Finally**

If the legal aspects of patients' health problems are not addressed, these outstanding legal problems can diminish or undermine the benefits accrued through delivery of health services. Some problems cannot be dealt with without legal advice. If you (the patient) have a health related legal problem or you think a patient may have one, make an appointment with the **HeLP** Legal Clinic lawyer. It costs you nothing.

**> Contact **HeLP****

Speak to an Alfred Health staff member to make an appointment today.

Supported by the Legal Services Board of Victoria

## WORLD HEPATITIS DAY — 28 July 2014

# Don't wait for warning signs



If you're living with HEPATITIS B or C (or think you may be),  
talk to your doctor about a regular LIVER CHECK-UP.  
It's easy and it could save your life.

## WORLD HEPATITIS DAY

hepatitis  
australia

National Infoline: 1300 437 222



[www.facebook.com/loveyourliver.com.au](http://www.facebook.com/loveyourliver.com.au)



[www.twitter.com/love\\_your\\_liver](http://www.twitter.com/love_your_liver)



LOVE YOUR  
LIVER

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

## THEME: Liver health check-ups

# A REGULAR LIVER CHECK-UP

simple, easy...and it could save your life

### WHY

have a regular liver check-up?

- If you've got hepatitis – hep B or hep C – you've got more risk of liver disease – things like cirrhosis (scarring), liver cancer, and liver failure.
- You may need treatment for your hep B or C even if you feel well.
- A regular liver check-up allows your liver health to be tracked. You can discuss with your doctor how to slow the progress of liver damage and decide when to start treatment.
- Talk to your doctor about getting a regular liver check-up.

### WHAT

happens during a liver check-up?

- Your liver check-up may start with a liver function test and other tests to measure how well your liver is working. These blood tests can be arranged by your GP or specialist.
- A FibroScan, or if this isn't available, a liver ultrasound, may also be done. The good news is that both are simple, easy and painless procedures.
- After your check-up, your healthcare professional can explain the results and discuss lifestyle changes, treatment options and the timing of your next check-up.

### HOW

often do I need a liver check-up?

- Depending on the results of your last liver check-up, you may be advised to have a regular liver check-up every three, six or 12 months.



Jen Anderson was diagnosed with hepatitis C in 1990. She received regular liver tests which helped her know when she needed treatment. Jen has been successfully treated and is now cured of hepatitis C. Jen says

**“I urge everyone who has hepatitis B or C – or think they may have – to get a regular liver check-up. Having regular liver check-ups helped me decide when to start treatment, which in my case was lifesaving.”**

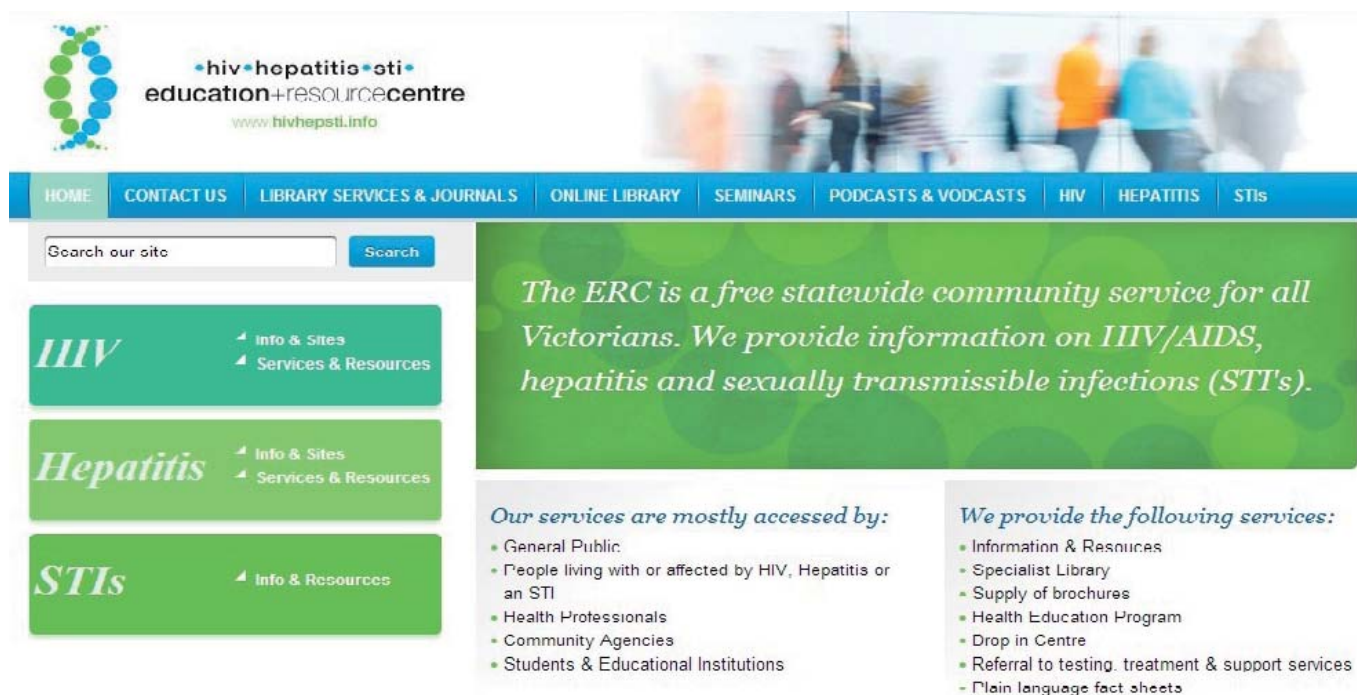
**A liver check is nothing to worry about.**

**Ask your doctor about having a regular liver check-up today.**



How can I find out more?  
[www.loveyourliver.com.au](http://www.loveyourliver.com.au)  
**1300 437 222**

hepatitis  
australia



The [www.hivhepsti.info](http://www.hivhepsti.info) website is a great resource for information. Andrea McColl and I attended a really interesting and valuable session that was recently run at Alfred Health regarding new medicine trials for people with hepatitis C.

This session was presented by Dr David Iser, a gastroenterologist and hepatologist. Dr David Iser has a similar presentation titled Direct Acting Antivirals: A new era in the treatment of Hepatitis C in podcast form on this website (details below) and is definitely worth viewing.

Julia Broadbent

[www.hivhepsti.info/podcasts\\_vodcasts.php?r=casts/render&id=112](http://www.hivhepsti.info/podcasts_vodcasts.php?r=casts/render&id=112)

**Hepatitis Champions Community Advocates** are campaigning for change in the Victorian Community. Our advocates use their personal experience of living with, or supporting others with viral hepatitis, to increase community understanding and awareness. This advocacy work is a powerful tool, designed to dispel myths and reduce stigma and discrimination in the Victorian community. This work is aimed at spreading the news about immunisation and treatment programs for viral hepatitis, with the long term goal of eradicating hepatitis in Victoria. It's a huge task and that's why we need your help!

You too can make a difference!

We are always on the lookout for new **Community Advocates**.

If you feel you would like to become a **Community Advocate**, or if you know of someone who you think would be open to committing their time and energy to this innovative project, please contact our **Hepatitis Champions Community Advocates** Project Officer, Jane Little, either via email on [jane@hepvic.org.au](mailto:jane@hepvic.org.au) or give Jane a call on 9385 9123.

All our advocates will receive full training and ongoing support. A Hepatitis Victoria initiative.

## STEPPING UP THE PACE – THEME OF AIDS 2014 CONFERENCE

The HIV and AIDS field has seen renewed optimism over the past few years with substantial gains made in cure and vaccine research, growing numbers of people receiving antiretroviral treatment, falling rates of infection and more evidence on Treatment as Prevention. However, this progress has not been universal with many regions struggling to address their HIV epidemic among a backdrop of ever increasing infections and difficulties in funding, implementation and political challenges.

Stepping up the Pace recognizes that we are at a critical time and we need to capture the optimism that has recently emerged and build on it to ensure that HIV remains on top of the global agenda. The pace needs to further increase to ultimately reverse the trajectory of the epidemic.

Stepping up the Pace reminds us that we have to energize and revitalize our efforts to increase investments, collaborative research and political commitment. This can be done through controlled and coordinated action, including significant programme scale-up in resource-limited settings, commitment to evidence-based interventions, and more effective and intensive interventions in “hotspots” where Key Affected Populations (KAPs) are being left behind. Crucially there is the need to involve KAPs and address the stigma and discrimination which they face, including punitive government policies.

Stepping up the Pace reflects the crucial opportunity that AIDS 2014 will provide for mobilizing stakeholders, joining forces and building on the present momentum necessary to change the course of the epidemic.

*- from AIDS 2014 Conference website  
[www.aids2014.org](http://www.aids2014.org)*



## Ageing Well: Maintaining health as we age

### An online course from Chronic Illness Alliance

We all want to age well. We want to be able to continue to do the things we need to do, as well as the things we want to do. This course was designed to provide older adults with a quick and easy check-up on how we can maintain and improve our health.

There is a large and growing body of evidence related to healthy ageing and this evidence has been used to develop the National Ageing Research Institute (NARI) Healthy Ageing Quiz.

The Healthy Ageing Quiz was designed to provide older adults with an opportunity to assess their current state of health using an evidence-based and user-friendly method. It is a quick and easy check-up to identify the areas of your health that need improving and provides specific recommendations for improvement that draw on the latest

research findings regarding healthy and positive ageing strategies.

The first part of this online course is the Healthy Ageing Quiz itself. Each of the following nine Units of the course are based on each of the important areas for healthy ageing:

- physical activity
- balance and falls
- smoking
- alcohol use
- diet and weight
- chronic conditions and medical care
- sleep and stimulating your mind
- social connections and productive engagement
- optimism and adaptability

As well as providing information and recommendations within each Unit, the course content includes a range of

resources that will help you if you make changes within that area of your health. Some of the resources will be materials you can download directly from the course and others will be suggestions and links to resources available on the web and in the community. There is also an online journal in each Unit called an “Action Plan”, where you can make notes to help you keep track of your new healthy ageing strategies as you work through the course.

Even for those of you who are already applying the recommendations made in the course, we hope you will learn something about factors that contribute to healthy ageing and get some more ideas about strategies you can use.

For more information about this course or to participate please go to:  
<http://plotproject.net/patce/>

## NEW HEPATITIS TREATMENTS....your views

Thank you to all the people who completed the HFA hep C new treatments survey – including the people who phoned their comments in.

### What's this all about?

The Australian Government asked for community comments about two new hepatitis C treatments, sofosbuvir and simeprevir, by 11 June 2014.

These new treatments are being evaluated by the Pharmaceutical Benefits Advisory Committee (PBAC) in July 2014 to see whether they are suitable to be subsidised through the Pharmaceutical Benefits Schedule (PBS).

HFA asked community members affected by hep C to explain what difference these treatments would make for them. The response was really powerful and has helped HFA to put together a very solid and meaningful submission.

We will report on the outcome of the PBAC meeting when the results become available later in the year.

### What are these new treatments?

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) to be effective.

Recommendations on how they should be used in people with hepatitis C are part of this evaluation process. Both drugs are approved for use in the United States and in Europe.

Professor Ed Gane from New Zealand explained more about these new DAAs at a recent conference in Brisbane – <http://tinyurl.com/new-hep-c-treatments>

Suzanne O'Callaghan  
Policy Research and Education Manager  
Haemophilia Foundation Australia (HFA)

To find out more about new and emerging therapies for hepatitis C call the Hepatitis Infoline 1800 703 003

Or go to these websites to find out more:  
[www.hepatitisaustralia.com/treatment-for-hep-c/](http://www.hepatitisaustralia.com/treatment-for-hep-c/)  
[www.hivandhepatitis.com](http://www.hivandhepatitis.com)      [www.hcvdrugs.com](http://www.hcvdrugs.com)

If you are thinking about undertaking standard Interferon/Ribavirin therapy check out the Hepatitis C: Treatment Side Effect Management Guide [www.hepvic.org.au/hepatitis\\_resources](http://www.hepvic.org.au/hepatitis_resources)

AND talk to your treatment specialist and find out about your current liver health and what your treatment options are.

## LADIES' DAY OUT

*Celebrating  
10 years of support!*



The "Ladies' Day Out" event is designed to provide a much appreciated yearly break from the routine and demands of women who are impacted in some way by Bleeding Disorders, either directly or as a caregiver or family member.

We offer peer support and an opportunity to try new, perhaps previously undiscovered, methods of relaxation and improved wellbeing.

New and renewed friendships are developed and support is provided in a carefully selected, fun environment.

So come and join other HFV ladies for a special 10 year anniversary pampering treat!

**True Thai Massage**  
**308 Chapel St**  
**Prahran**

**Sunday 19th October 2014**  
**11.00am**

**Followed by lunch at a local café**  
**(TBC) 1.00pm**

Bookings essential either on 9555 7595 or through our website. Numbers limited to 20 so book early to avoid disappointment.

A \$5 contribution is appreciated on the day.

## ATTENDING A HAEMOPHILIA CAMP — THE FIELD FAMILY'S EXPERIENCE

As HFV members some of the questions which we ran through each time as a family when we heard about the annual Haemophilia camp were;

*Is our family ready for a camp? Now, that we are dealing with Adam having an inhibitor and not having great balance?*

*Are we going to be more stressed in a camp environment about what might happen? And how are we going to cope?*

*How are we going to administer our Factor VIII and make sure everything is sterile (as Adam has a port) outside of the comfort of our home environment?*

*Will we know anyone at camp & will Adam & Emma our children enjoy the experience or feel out of place at camp? Is it worth going?*

Our family's background is our son Adam has Haemophilia Type A, Severe and he suffered an intracranial bleed at birth. Adam also developed an inhibitor just before he turned five years old and had a port put in, which enabled Adam to receive daily doses of his factor easier.

Well, I am happy to say that our family took the plunge and has been to two camps now and found the camps to be an awesome family experience (as Adam and Emma both describe the camps). The other families that have attended camps before are more than helpful and welcoming to new families. You come away with a real sense of community out of the whole camp experience.

Purple Soup employees, who ran the camps we attended, made sure every child felt special and every adult was included. Our daughter Emma who thought the children who had Haemophilia would be the only ones getting attention soon found out that wasn't the case.

As parents, Grant and I saw remarkable changes in our children where they would attempt every

activity, pushing themselves outside of their comfort zones (which they still talk about) in a no pressure, fun environment.

Grant and I enjoyed the "adult time" where the men go off as a group and do men's stuff, sharing experiences, etc and the women do the same in a women's group. At the last camp, I had the biggest strawberry daiquiri I had ever seen! This is the time when lasting relationships are made between families, even though you may not catch up with them again until another Haemophilia event is run later in the year.



For our family, the camps have been a great experience. When Adam saw other children receiving and some administering their own factor he realised he wasn't the odd one out. Adam commented to me "most of the other kids have ports too"? Adam thought that was cool. As parents, Grant and I learnt to let go. It was OK for Adam to be off attempting activities under the supervision of others.

Now, in our family when we hear the camp is coming up, the only questions we consider are: when? And where? Because we will definitely be there!

PS Adam no longer has an inhibitor, has really good balance and is on factor every second day.

Donna Field

## BRADLEY'S STORY

Bradley was diagnosed a day after giving birth to him with severe Haemophilia A Factor VIII and little did we know what was to come or how to deal with it all.

We first started treatment at the Royal Children's Hospital in Melbourne under the team of Dr Chris Barnes. We received a lot of information and material about the condition as well as how to administer treatment. Back then, Bradley was only three months old when we got seen on a regular basis for check ups, as he was only on demand treatment. He had his first buttocks bleed when he was around one year old. We rushed to Emergency and got seen very quickly. He needed his factor for the first time in his life, and getting a one year old to sit still for an intravenous injection is not an easy task. I actually ended up breast feeding him and holding him tight for them to find the vein and do their thing. At the end he was so exhausted from fighting the doctors that I could barely calm him down. At that stage I was dreading any further treatment not knowing how we would ever cope if we had to do this ourselves.

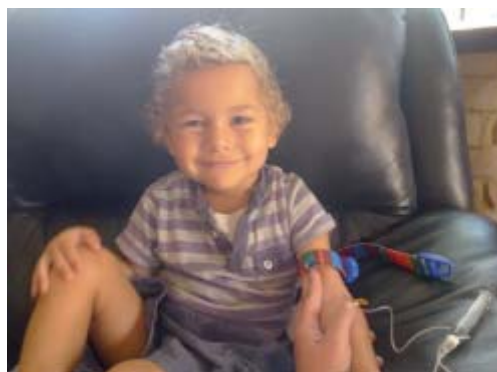
A new job opportunity for Brian meant a move to Perth was on the cards. I remember us driving from Melbourne to Perth with the kids in tow and praying that nothing happens to Bradley whilst on this journey. Every time we opened the cooler box and the little box of Factor glimpses at you, you start to realise how vulnerable you are as a parent should something happen in the middle of the Nullabor with no experience on how to give him his treatment if you ever needed to. Lucky for us, we arrived in Perth safe and sound.

The Melbourne team had already given the Perth team a heads up that we were coming and after just two days in Perth I received a call from Sister Lee, welcoming us and giving us an appointment to meet Dr Price. After a couple of months of us getting regular check ups, as well as the occasional emergency trip to the hospital as Bradley got more and more muscle bleeds or big bruises, Dr

Price and Sister Lee suggested to put Bradley on prophylaxis treatment once a week. That meant for me to bring my little man up to PMH every Tuesday morning for his 500ui Factor Treatment.

I clearly remember the nice drive into Perth to be followed by dreading how to find a car park and how Bradley would behave to get his Factor. He enjoyed the trips to the Hospital, playing with the Volunteer ladies in the waiting area and getting to know all the doctors and nurses. Up until the point, when I would take the Emla Cream off, that's when he started to realise what is to come.

Fortunately for us, Bradley has very good veins, but despite that we struggled giving him his Factor. It usually took 4 of us to hold him down. We started off wrapping him up in a blanket so that he would lay still, followed by sitting on my lap and eventually sitting on his own to get his Factor.



He was fighting everyone off and half the time it took us several tries and several veins in order to get his Factor in. Occasionally we had to go home with no treatment as he was just not sitting still enough. Of course, we heard the suggestion to get a port as this would be much easier to administer his treatment and eventually we could do the home treatment ourselves. It sounded great to me. I had it in my head that this was the way forward, yet for Brian it was a no go. We spent many hours discussing the pros and cons between the port and the IV treatment. Bradley was scheduled to have his operation in January 2013 and all fell through

a day before the operation due to our private insurance not being willing to cover the costs.

Looking at it now, it was a God send, but back then I really did not know what the future would hold carrying on with the Tuesday trips to PMH. So we carried on visiting Sister Lee every Tuesday and as Bradley got older and more active we also visited on other days. I also need to mention that as he got older, the more he got used to the Tuesday trips and the routine that a Tuesday morning meant for us as a family. He started being much calmer and letting the doctors and nurses do their job.

It was October 2013, and I remember clearly that we had another scare and had to rush to hospital. It was time we made a decision on how we can treat him at home. Since we were still very unsure about the port, we decided to see if we can inject him ourselves. The team at PMH started teaching me how to put the factor together, how to make sure everything is sterile, to prepare Bradley and of course how to find a vein and needle him. This procedure took a few months to master and for me to be confident in what I was doing.

I also remember that in January 2014 he had a pretty bad fall at home and needed his factor. I decided that this was the night to give him his first factor at home. I still remember how nervous I was, and how the sweat just kept pouring down. It was incredibly hard to overcome the first hurdle of knowing this is it. He needs his factor now and he depends on you. I missed the first vein and had to take a few big breaths as we changed arms. Bradley was perfect, sitting still and playing in his sticker box. "I got it", I said to Brian and the rest was teamwork.

Next day coming into Hospital I remember how proudly I told Sister Lee what I did and got the biggest hug ever. It felt so good. Needless (pun) to say that the start of home treatment was still making me nervous but if all went well we could have a new home Tuesday routine.

Looking back, it seemed a long way to go, to be where we are now. I have visited PMH every Tuesday for one and a half years. Made the oc-

casional Emergency trips down there and had to worry about Bradley whenever he got hurt or was just not himself. Having decided not to go for the port was, for our family, the best decision. He calls me doctor when we now inject him. We have our favourite veins and usually hit them first time.



Bradley sits still even checking if Mummy and Daddy do everything right. He is now at the stage that he wants to help us giving him his factor. Two years ago he did not even want to know about it. Endurance is probably one word you could use, but I am immensely proud of my 2 year old Bradley who has mastered such a milestone in his life.

Grit Hadamschek Bradley's Mum

## Advocates in our community

*Reflecting on the congress, we as an organisation have come away with a strong feeling of commitment, enthusiasm, and desire to improve the lives of those affected by bleeding disorders in our community. As you may have already read about we have now developed our plan for 'building a strong future at HFV'.*

*What struck a real chord with me during the congress was what a strong community group we have in Victoria. Whenever I looked around I saw a number of our members in their bright yellow shirts. They were the ones who had volunteered to help at the conference. This job in my mind entailed directing people to the sessions, scanning registrations and handing out pamphlets. What I soon realised was there was a much more important role that many volunteers took on - and that was connecting with people.*

*One of the Volunteer Coordinators at the congress was Carol Ebert. Carol is an active member of our committee. Whenever I saw Carol at the congress she was on a mission — moving at a million miles an hour, with a walkie talkie in hand and only slowing down enough to tell me that she had met a new person, she'd connected with them, she had their details, she'd introduce us and that she always did!*

*When Carol joined our committee she wanted to be involved. As a grandparent she was unsure in what capacity she could help and what she could offer our committee and community. Well, Carol has certainly found her feet. In my eyes Carol is a true advocate for our community and much more than she is aware. She has a knack of connecting with people on their level, she is approachable, pro-active and has a clear understanding of how she can make a difference.*

*When I saw Carol at the congress I felt proud that she was on our committee. I felt proud of all our committee members - of their dedication and commitment. I felt proud that Carol and our committee were representing us, HFV, on a global level. I came away with a strong sense that our community is made up of a diverse mix of people but all with the same common goal of wanting to build a strong future for those with bleeding disorders in our community - locally and globally*

*Our own President, Ann Roberts, was on the WFH Congress Organizing Committee and had a great deal*

*of involvement in the planning of the congress. Ann has been involved with HFV and HFA for many years and has played a huge role in advocating for a better future for our community. Ann was also very busy at the congress racing from meetings to stall duty to interpretation desk duty and back to meetings! Ann just gets on with it - doesn't make a fuss and really does deserve to be recognised by our community for all she has done and helped achieve over her many years of service.*

*To our HFV committee; Carol, Ann, Leonie, Jodie, Zev, Michelle, Matt, Damian, Sharron, Donna and Karen, you all deserved to be thanked for your dedication and commitment to HFV and the people we support.*

*We've got a great team - and always opportunities for you to join us in various capacities!*

*Julia*

*\* Additional note from HFV President Ann Roberts:*

*I would also like to add a personal thank you to both our staff, Julia and Andrea. With their dedication and support we as a committee are able to support our community to the best of our ability. They both work above and beyond the call of duty to ensure member events and programs are available to all members and to go that extra mile to ensure a positive outcome for our community.*

*On behalf of our committee I would like to acknowledge their hard work as it is truly appreciated. Ann*



*Leonie, Julia, Carol & Michelle - celebrating the success of the congress!*

## ATTENTION ALL CAMPERS!!!!!!

*2014 family camp....*

Sat 22nd — Sun 23rd November

BOOK NOW for a one night  
family camp to Lake Dewar.

Run in conjunction with the RCH team!!!

*Not been to a HFV camp before?  
Want more info? Why not chat to our staff, our  
committee or the RCH team.*

BOOKINGS ESSENTIAL - SEE THE ENCLOSED FLYER

### GRANDPARENTS & FRIENDS LUNCH

*You are invited to join our annual Grandparents and Friends Lunch at the beautiful  
'Madeline's At Jells'. Weather permitting we may take a stroll around the park so please  
bring your walking shoes!*

This get together provides grandparents and friends of those with bleeding disorders the  
opportunity of valuable support and information.

Sunday 24th August 2014, 12.30pm — 2.30pm

Madeline's At Jells, Jells Park, Waverley Rd, Wheelers Hill

2 course lunch, a glass of wine & coffee —  
all provided courtesy of HFV

Bookings essential on 9555 7595



## our community

### REGIONAL VISITS 2014

Horsham 10th August  
12pm @ RSL

**YOUR REGION NEXT?**  
CALL US IF YOU WOULD LIKE  
HFV TO VISIT YOUR  
REGION IN THE FUTURE

*Lunch will be provided by HFV.  
Check our website for more details.  
Bookings essential*

VIC  
TOR  
IA

### RIDE FOR HAEMOPHILIA

MELB → SYD

PERTH → ADELAIDE → MELB

*...supported by HFV*

Stephen is a 33 year old Victorian with haemophilia and asthma, who is keen to test his health and fitness level whilst also hoping to raise awareness of haemophilia and see more of the Australian countryside!

The trip will be in 2 phases, Melbourne to Sydney/northern NSW by push bike, a distance of approximately 1200kms, to be followed by a train ride from Sydney to Perth on the Indian Pacific. From Perth, Stephen will cycle from Perth, along the south west of WA to Esperance, then re-joining the Ayre Highway to Adelaide and back to Melbourne, this would add another 3500km. A total distance of nearly 5000 kms!!!

If you would like to support Stephen please go to: [http://personalchallenge.gofundraise.com.au/page/Randall\\_Stephens](http://personalchallenge.gofundraise.com.au/page/Randall_Stephens)

Check out his progress at [randallstephens.blogspot.com.au](http://randallstephens.blogspot.com.au)

**GOOD LUCK STEPHEN!**

### CARRIER INFORMATION SESSION

HFV is looking at running a carrier information session in  
September, October or November 2014

We are currently reviewing possible issues and topics to cover.

Your input is valuable so please contact our office on 9555 7595 or email [julia@hfv.org.au](mailto:julia@hfv.org.au) if you have any suggestions on what you would like addressed.

## 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  
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](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  
Daniel Bostelman | Hepatitis C &  
Haemophilia Social Worker  
Abi Polus | Physiotherapist

## HFV Membership Renewal Subscriptions

Renewal subscriptions for 2014/15 were mailed out at the beginning of June to all members.

Payments are now OVERDUE.

Please make payments ASAP.

Thank you.

## HFV MEMBER SERVICES

### Membership Fees:

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

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

### Ambulance Subscription Subsidy:

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

### To obtain an Ambulance Subsidy:

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

### Other Subsidies:

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

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

### Care and Counselling:

This is available through your treatment centre.

### Magazine:

Your quarterly magazine offers information and details of upcoming events.

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

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

### The HFV Office:

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

### We are located at:

13 Keith Street,  
Hampton East, Victoria, 3188.

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



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