

# THE MISSING FACTOR

CHALLENGING  
OUR CAPACITY

2018 REGIONAL  
VISITS PROGRAM

11 Locations

Consumer  
Participation  
in Research

connect • support • empower



# AUTUMN 18

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HFV is committed to Child Safety.

Our Child Safety Statement is available for review on our website [www.hfv.org.au](http://www.hfv.org.au)

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

Opinions expressed in The Missing Factor do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres. The content of this publication is provided for information purposes only. All information is provided in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. No claim is made as to the accuracy or currency of the content at any time. HFV do not accept any liability to any person for the information which is provided.

HFV is funded through the Department of Health and Human Services under Blood Borne Virus Sector - due to the historical impact of contaminated blood products on the haemophilia community. HFV supports our diverse community and our magazine reflect topics that impact our community including Bleeding Disorders, BBVs, Mental Health and positive health promotion.

Editor: Julia Broadbent



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.





# PRESIDENT'S REPORT

## CONNECT SUPPORT EMPOWER

Welcome to 2018. Hope everyone has enjoyed a happy and safe new year whether it be 1st January or more recent Chinese New year. Whatever you celebrate I hope it has been wonderful and some quality family time.

It may only just be March but I assure you HFV have been very busy already. As far as peer support programs we are already up and running. The men's retreat has had another successful weekend and a fun day for our youth attending Dialogue in the Dark, playing golf and hanging out. Lots of other activities are also planned as HFV committee have worked hard at finalising our yearly planner.

HFV are gearing up for yet another exciting year and hope to see many of you at various events planned. Community camp is nearly here with bookings now open. It is one of the biggest events on our calendar and we encourage everyone to consider joining us. It is not just for the young but also the young at heart so there is a place for you either solo or with company.

We are very excited to announce a new regional visit plan to increase HFV's capacity to get out to as many areas as we can. Details in the newsletter so please see if there is an opportunity for you to join us somewhere along our road trip. It should be amazing and the committee are all excited to be a part of the plans. We also have a walk around Albert Park planning for Bleeding Disorders Awareness Week.

Committee has also worked hard on the strategic plan. As you know we have requirements to acquit for our generous funders at Department of Health and Human Services. However we also have a broader responsibility to you as our members. Taking time to develop strategic plans is critical to us as we consider best ways to connect,

support and empower our community. We encourage everyone to be a part of this work and welcome any conversations with any of our members to contribute your views at anytime on the priorities and types of activities we need to work towards.

The committee also took time for some critical training to develop our understanding of the issues that impact on all of you. We have revisited the theory of peer support and Julia delivered a very impressive Power-Point as a discussion point to ensure our programs are articulated clearly to assist in achieving our goals. We had a session regarding Child Safe policies and building our understanding of what HFV's responsibilities are for children at risk that may come to our attention through our peer support activities. Very critical education and the beginning foundation for further work in this space.

We also had a session to build our knowledge on family violence both in elder abuse as well as violence against women and children. Violence against women is now recognised to be a serious and widespread problem in Australia, with enormous individual and community impacts and social costs. Why does HFV need to understand family violence? Just a few facts to put this in context:

- On average, one woman a week is murdered by her current or former partner, according to the most recent analysis of homicide statistics in Australia
- The combined health, administration and social welfare costs of violence against women have been estimated to be \$21.7 billion a year, with projections suggesting that if no further action is taken to prevent violence against women, costs will accumulate to \$323.4 billion over a thirty year period from 2014-15 to 2044-45
- Intimate partner violence contributes to more death, disability and illness in

women aged 15 to 44 than any other preventable risk factor.

As we value the role of peer support and building resilience within our community we cannot ignore that our community face many social issues beyond their health. As part of this responsibility we believe as a committee we should have some understanding of these significant social problems to ensure we are able to make great referrals to support you as our community if you come to us for support.

For those that wish to discuss further any of these topics please contact HFV to chat to staff or below are some useful websites:

For support if you are experiencing family violence please contact [www.1800respect.org.au](http://www.1800respect.org.au)

For men that would like support to discuss your relationships please contact [www.ntv.org.au](http://www.ntv.org.au)

For those with any concerns regarding the safety of children please contact [www.childsafe.org.au](http://www.childsafe.org.au)

At HFV we are committed to strengthen structures around our agency to enable the great work we do to continue. We welcome Robyn to our committee and say goodbye to Kate and thank here for her time on committee. We look forward to yet another exciting year at HFV and working with you as our community. Don't forget the financial support available for member such as ambulance subsidies and Live Well Funding.

As always stay safe and don't hesitate to get involved. There is always an opportunity for you to be involved and we would love to have the chance to chat. Hope to see you at an event soon!!

Leonie Demos - HFV President

We are seeing many new opportunities for consultation about treatment products. This is due to more and more products entering the market leading to increased industry competition and complex government processes for funding new medicines. Even if treatment products are registered for use as safe and effective, government payers are seeking more sophisticated ways of measuring the potential outcomes of the funding they allocate. In the world of bleeding disorders it can be difficult to measure cost effectiveness, and compare outcomes and costs as the new therapies continually add more possibilities and potential outcomes. We are rarely comparing apples with apples these days, but governments will make decisions around what they will pay for. We need to influence this.

# Consumer participation IN RESEARCH

When these new treatments are being considered for government funding some of the tools used to evaluate their cost effectiveness do not take into account the things that a user (patient or carer) might think are most important (eg less infusions, improved veins, higher trough levels, less/no bleeds with longer acting factors, for example).

It is more and more important for our community members to express their views and share their experiences about living with a bleeding disorder, what they think is most important for their treatment and treatment outcomes. But our community has had to deal with a lot, and we observe many of our members are uncomplaining and stoic. Some are tired of providing their views, while others don't think their views would make a difference. But we are very much at the 'pointy end' now. We need people to respond, because their views may well tip the scales, and make the

very difference we are seeking. It is the personal experiences that are often missing from some research project reports.

We need to increase participation, and get the views of the people using the treatments. It is their experiences that are so important for informed decision making and advocacy.

## ***But how can we do this? How can we get their views?***

Participation in research is one way that information can be collected and passed on to decision makers. The research may be our own, or it may be academic research, or research undertaken by pharmaceutical companies seeking information to guide their decision making about their treatment products or their future pipeline.

To encourage people to understand how research can lead to better treatments and care HFA has a section on the website and we often list research that people may wish to be involved with.  
[www.haemophilia.org.au/research/participating-in-research](http://www.haemophilia.org.au/research/participating-in-research).

We encourage all our foundation members to look at this from time to time. Currently there is a patient preference study advertised where the researchers are seeking people with inhibitors (or their carers) to respond to a half hour on-line survey. This could very much help future treatment and experiences of people living with inhibitors. Please encourage anyone you know who might wish to participate.  
[www.haemophilia.org.au/HFA/media/Documents/Research/CaPPRe-REHA-Patient-invitation-2017.pdf](http://www.haemophilia.org.au/HFA/media/Documents/Research/CaPPRe-REHA-Patient-invitation-2017.pdf)

**Sharon Caris**  
**Executive Director**  
**Haemophilia Foundation**  
**Australia**



It is more important than ever for the community to express its voice, and for individuals to explain their treatment needs and what they want to achieve from their clotting factor or other therapy. In recent years, more and more Australians with a bleeding disorder have had the opportunity to participate in clinical trials. This is a courageous decision as it carries risks. It is often quite onerous, with lots of visits to the HTC, lots of recording keeping. Sometimes the outcomes of a new treatment are very obvious, at other times less so.

# ASK US...

## Q & A's with Alex & Jane

### YOUR QUESTIONS FOR THE ALFRED HTC TEAM

***I live in the country and am wondering what happens when I come to the Alfred Haemophilia Treatment centre?***

When you come to The Alfred HTC you will meet a number of different people, all important for your care. You will be welcomed by Susan in the office, you will meet with the doctor, the social worker, the physio and the nurse, you may also meet the data manager and the psychologist. All of these people can help you. The Alfred HTC is the state-wide treatment centre for haemophilia and other inherited bleeding disorders, so we have many country patients. All patients are recorded on the ABDR, this helps whenever one of our patients needs any treatment, we will talk to you about the ABDR and ask for your consent to be on the ABDR.

Anyone living more than 100kms from the Melbourne CBD can claim reimbursement for travel costs when coming to an appointment and accommodation if they are required to stay overnight for any medically sanctioned reason. We encourage all regional patients to utilise The Victorian Patient Assisted Travel Scheme (VPTAS). It requires a claim form and the social workers can help with this. The forms are available on line or from social work. If you are attending other specialist appointments (a part from the HTC) at the Alfred, please ensure you have a separate VPTAS form signed off by the medical officer you are treated by.

If you need to stay in Melbourne, the Social Work team have a list of local hotels and places to stay. If you have any particular issues associated with transport or accommodation the social workers can assist with these too. Some country towns have a great community car system, and this is really helpful when you can't get yourself down to Melbourne.

For country patients we recommend

a visit to the local GP and may save a trip into Melbourne. The HTC is able to guide and inform the regional medical service depending on the nature of the medical issue. In some cases it may require the patient to be sent to Melbourne by road or air ambulance for further investigation and treatment or a supply of treatment can be sent urgently to the regional hospital to administer. If you are on regular prophylaxis, keeping your treatment records up to date on the ABDR will also help the HTC team monitor your health and alert them to any concerns.

Some regional patients, depending on their haemophilia status, are seen for yearly review and this appointment will be sent to you. We also like to give you a text reminder a few days before your appointment.

***What is the transition process and how involved can parents be?***

The transition process begins long before the young person has their first appointment at the Alfred Hospital. All through the treatment at the Royal Children's Hospital the team, including parents, teachers, nurses, doctors, physics, social workers, are helping the child to learn about their condition, become independent with their treatment, and prepare to shift to an adult treatment centre at the appropriate time. This transition usually happens after the young person finishes school, but there are many factors which influence this timing. Ideally, the young person will get to know some of the team from the adult centre, and also get to visit prior to their transfer of care. Several meetings are held between the RCH and Alfred HTC teams to discuss and hand over information.

The Royal Children's Hospital Haemophilia Treatment Centre team arrange a final review clinic where they will say a formal goodbye and to prepare the young person for the next stage in their treatment. A written

summary is arranged to be forwarded to the Alfred HTC. At this point an appointment is made for the young person to come to the Alfred. When possible we have a special clinic for transition, in which we allocate more time to get to know each new patient, and to talk about their needs.

Parents are encouraged and welcomed to transition clinic and we think it is supportive for the young person and helpful for the Haemophilia Treatment Centre team. However it is important for families to remember that the young person is now becoming an adult and will be seen by themselves, at least for part of the appointment. Often the way it works is that the doctor talks to the young person alone and then invites the parent/support person into the room after a while. This gives the opportunity for privacy and developing independence and also a chance for parent/support person to find out what is going on and ask any questions that they have. This can only happen with the consent of the young person.

The Social Workers (Jane and Alex) are always available to talk to parents and significant others about any concerns. Sometimes the process of growing up can put some distance between parents and their children, and we know that it is hard to watch from the sidelines after having put so much into looking after your child. Sometimes they will make bad decisions, but it is important to remember it is their decision to make. Likewise, it is difficult for some young people who are ready ahead of their parents and who want to manage their health care by themselves. Please let someone in the team know if this sounds like your situation. We will try and support you all as much as possible.

**Jane Portnoy & Alex Coombs**  
*Social Workers, Haemophilia & Other Inherited Disorders Team*  
**ALFRED HEALTH**

Please send your questions for the next edition to Jane, Alex or to the HFV team by the 1st May. You can remain anonymous, use an alias or just your first name. J.Portnoy@alfred.org.au, A.Coombs@alfred.org.au or julia@hfv.org.au





# Challenging our Capacity...

with a bit of luck & determination

*At seventy-one and looking back at life with Haemophilia B, I sometimes wonder whether I've just been lucky to have survived given my early ignorance about risks associated with the disorder and my determination - probably unwisely - not to be constrained when it comes to physical activity.*

*In 1960, at the age of fourteen I took part in an investigation at the Alfred Hospital, led by Dr Ronald Sawers. This had followed severe bleeding after a tooth extraction requiring admission to the hospital for treatment. At that point, I was diagnosed with mild Haemophilia B, i.e. factor IX deficiency around 10% of normal. Dr Sawers extensive investigation documented the familial lineage of bleeding tendency across our extended family, although other immediate family members did not appear to have this specific factor deficiency. As a young child, I had survived tonsillectomy which resulted in very serious life-threatening bleeding, as I understand it. Dr Sawers subsequent investigation in 1972 confirmed his earlier conclusions.*

*In the meantime, I had continued to do everything I enjoyed in terms of physical activity: particularly football throughout my teenage years, and running. I was never a really good runner, but I enjoyed my runs along the Yarra in the early days, and then other*

*tracks around home, which was Heathmont at the time. I enjoyed competing in lunch time corporate cup events around the tan (Botanical Gardens). My regular track now is more likely to be the Inverloch surf beach.*



*On reflection, the football career was never going to be a good idea having more than my fair*

*share of injuries. I had graduated to competitive squash. In those days squash was a popular sport and demanded a high level of fitness.*

*The biggest risk for me, and without going into too much detail, appeared to be the social side of the sport. Nevertheless, I had met some wonderful friends and characters during that time. The squash continued for many years without any serious bleeding related injury, as did running which is still a regular commitment for me, although these days, I mix things up quite a bit: resistance training (weights etc), running, cycling and swimming.*

*Carmel and I were married in 1969 and went on to have four beautiful daughters, all of whom, of course, are haemophilia B*

*carriers. We have six grandchildren, including two boys with the mild factor IX deficiency. We are*



hopeful that advances in current research around gene therapy will directly benefit our grandsons and others with this genetic condition.

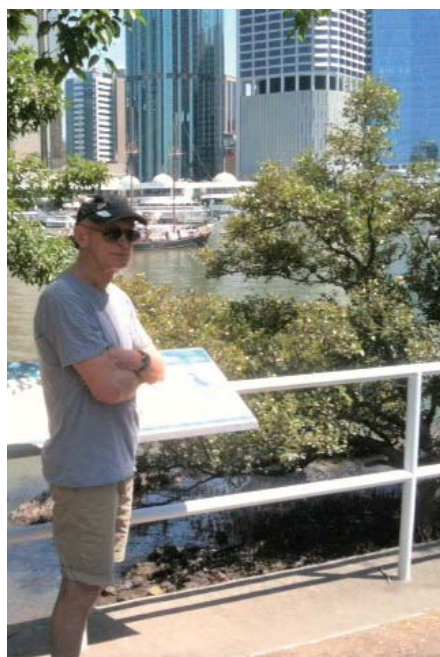
There have been some interesting events for me in more recent history. In 2009, in preparation for prostate biopsies, I received factor IX at the Alfred Haemophilia Centre. At the same time, it emerged that I had Hepatitis C and had carried the virus over a long time. Clearly, this was due to receiving contaminated blood product around 1980 in relation to surgery at the Alfred. Over a period of about twenty-five years with Hep C, I continued with running and other physical training, oblivious to the Hep C.

I then participated in a clinical trial at the Alfred with treatment using interferon and ribavirin. Overseen by Dr Stuart Roberts, Head of Gastroenterology at the Alfred, the trial was a challenge, and it was obvious that I would not be able to continue my level of physical training, but I was determined to do an hours walk each day which I believe, helped in dealing with the side effects of the drugs over forty plus weeks. The trial was successful with complete clearance of Hep C.

In 2011, I was working as a production systems coordinator in the dairy processing industry and had an accident on site. I received treatment at the local

clinic for what was thought was a bruised lower leg, and sent home.

It quickly developed into a huge haematoma and bleeding into the leg cavity. I then had to travel to the Alfred Hospital (two hours away). The hospital treatment - factor IX and plastic surgery - was swift and probably saved the lower leg. I did reflect however, on the potential for far worse outcomes for me, and others with haemophilia, due to lack of factor supply at larger regional hospitals. Although, I believe that the Alfred is the place to be if circumstances permit.



For many, intensive exercise may not be an option in managing haemophilia. However, in my circumstances, exercise has been a consistent theme in managing

my deficiency and in motivation for bouncing back after an injury, or for example, surgery. If the option is there, I would highly recommend a variety of forms of exercise as part of our lifestyle routine, especially exercise that challenges our capacity.

Soon after writing this and coincidentally, I experienced serious bleeding after a procedure to remove a skin cancer from the chest. The cancer turned out to be non-malignant, however the bleeding incident required transfer to the Alfred. Once again, I was amazed at the seamless and timely action, and the professional coordination that was clearly routine for the Haematology Department/Haemophilia Centre and Plastic Surgery Department. On discharge, senior Haemophilia Centre Nurse, Penny McCarthy politely chastised me and offered the advice - "Ern, remember, anything involving a scalpel, come straight to us".

Once again, it's great to get back to running, swimming, gym, cycling etc - with due care of course!

Ern Cattach  
Inverloch

**We all have a story to tell. If you would like to share your story with our community, please email [julia@hfv.org.au](mailto:julia@hfv.org.au) Many thanks.**



# PEER SUPPORT

## what does it really mean?

Our HFV committee and staff recently held a strategic planning day which also involved us looking at a number of other areas that included Child Safety, Family Violence and Peer Support. I delivered a short presentation on Peer Support that served as a reminder of what our roles are as peer supporters.

Whether it be a camp, Men's Retreat or Christmas Picnic we are not only there to connect, we are there to Support and Empower each other through Peer Support and help ensure positive health and well being for everyone.

Here is some of the information that was shared on that day

### What is Peer Support?

Peer support is a system of giving and receiving help founded on the principles of respect, shared responsibility and mutual agreement of what is helpful shared experiences of emotional and psychological pain.

- Peer support is an intentional relationship between people who can understand and deeply appreciate how they are "like" each other.
- Peer relationships support transformation and growth for people with shared life experience.

- Peer support is an important component of one's recovery; it demonstrates hope, optimism & self-responsibility in a relationship between equals.
- Peer support provides opportunities for people to "give back" and support others = mutual empowerment.
- Peer Support is an integral part of supporting recovery
- Repeated face to face contact promotes trust and sharing of experiences.
- It gives any individual group member access to a range of peer views on any specific topic or issue

- Informal social events can provide a non-threatening way for new people to become involved.

### Fundamentals of Peer Support

The fundamentals of Peer Support really come down to **effective communication**

As a Foundation our members need to recognise that HFV offers programs and initiatives to facilitate peer support. This is communicated through the magazine in peer articles and through member programs.



For HFV Members: our members can facilitate positive impacts on peer health self management and on social and emotional wellbeing.

### How to facilitate effective peer support:

Active Listening -

- to use open-ended questions
- reflect feelings
- provide affirmations while avoiding communication roadblocks
- knowing how to say things without judgment
- to reflect empathy

Through storytelling –

- peers can reveal their vulnerabilities and strengths,
- reinforce their peer identity
- building bridges that transcend culture, age, and social status.
- whilst sharing lived experiences, peers can model positive behaviours
- motivate peers in their own self-care.
- importantly, storytelling is non-confrontational.

Story telling can be around a table at a family camp, it can be at a peer event or through the magazine. It doesn't need to be a two way conversation but can have the power to empower. People take away what they have heard and gain confidence in their own story.

It is very important not to over share or dominate:

- People don't feel safe talking about their life if the other person needs to out-do them with their horror stories.
- Don't out-talk people, or compete with me or they may clam up and stop talking.
- Stories about what went right are especially good. Or if a conversation does go down the road of what went wrong try to steer it around in a positive way to how you got through it or what you have learnt.

What are the boundaries of

### Peer Support?

Formal guidelines and boundaries for peer support are relevant for a formal setting like a sit down peer meeting. Our settings are quite different usually being a more informal formats but some of the guidelines would still apply. The guidelines and boundaries are set to ensure everyone feels safe and comfortable in the peer setting.

Formal guidelines would advise a mutually agreed conversation takes place regarding what is acceptable at the start of any interaction. This is not practiced by us as such but it is good for members to discuss mutual acceptable boundaries at the start of their conversations and HFV committee will endeavour to highlight this at the start of peer events.

### What should we be including in the boundaries guidelines?

- Respectful conversations
- Listening
- Non judgmental
- Sharing contact detail? Maybe start with just an email address
- Meet in mutual venues
- What if you feel overwhelmed by a peer? - seek support and guidance from HFV committee and staff
- Medical advice? Medical advice should only be provided by a healthcare provider. Always refer peers back to their healthcare providers so they can obtain the correct medical advice for their needs.
- Privacy - do **not** share information offered by peer.

Julia Broadbent

References:  
[www.peersupportvic.org](http://www.peersupportvic.org)  
 Centre of Excellence in Peer Support  
 Chronic Illness Alliance PLOT  
 Mead 2001  
[mypeer.org.au](http://mypeer.org.au)

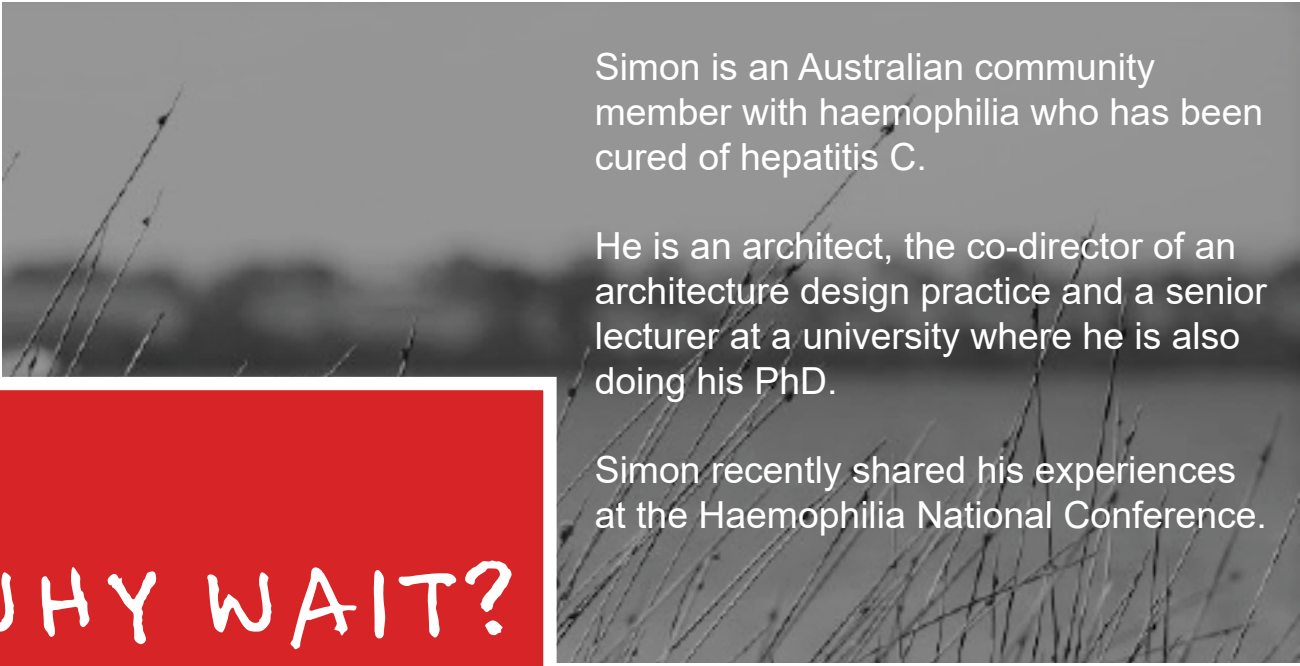
**HFV Peer Support Guidelines can be viewed through our website. [www.hfv.org.au](http://www.hfv.org.au)**

## YOUTH EVENT

# ESCAPE ROOM CHALLENGE

We are running a Youth Event for ages 16+ in Melbourne during the June/July school holidays.

The date is to be confirmed but if you are interested in joining me (Scott McDonnell) and a few other youth for a great event, please contact the HFV office and register your interest. Check [www.hfv.org.au](http://www.hfv.org.au) for more info



Simon is an Australian community member with haemophilia who has been cured of hepatitis C.

He is an architect, the co-director of an architecture design practice and a senior lecturer at a university where he is also doing his PhD.

Simon recently shared his experiences at the Haemophilia National Conference.

# WHY WAIT?

## A personal experience of Hep C treatment

Preparing this presentation began with me wondering what it was that I could bring to the Conference regarding my experience with hep C and its treatment. I mean, a guy in his mid-40s takes a pill with no side effects for three months and is cured of a disease without any residual issues is hardly compelling listening. In conversation with Suzanne from HFA though, my jaw dropped when she told me that some people had not taken up treatment. I couldn't believe that anyone would refuse the opportunity to finally rid themselves of that bomb ticking away inside them.

So I thought, well then, this is going to be about me giving reasons and experiences that you can relate to patients you encounter. Patients that may have reasons to avoiding or delaying taking up this quite amazing treatment. So I thought I'd imagine what those could be.

### 1. For those who are perhaps suspicious

As I, or I should say my mother and I, were in the early 80s when all

of a sudden treatment became dangerous. It was about 1984, a year or so after I had already contracted hep C from blood products taken for a couple of tooth extractions. Never mind the opportunity to contract HIV had probably already come and gone, the fact was that trust in treatment had evaporated.

So what to do? As a mild haemophiliac I had the option, for the most part, of just waiting out the slow healing of my joint trauma injuries. And my mum, keen to find some way to ease my pain and bleeding from injuries to my joints looked into alternative medicines. Safe medicines, and as it turned out quite useless ones.

I recall lying on my couch strapping cotton wool soaked in arnica to my knee, or ankle, or elbow – tinctures - for years, of unnecessary pain and lost days suffered. It still makes me very

angry to think someone, an adult, advised a haemophiliac child and their mother to undertake such nonsense.

So for those who are suspicious, I've tried things that don't work too, and I also had good reasons. This treatment we are talking about isn't that.

### 2. For those who have already lost time

I avoided any form of treatment for hep C following my ultimately unsuccessful interferon treatment in my early 20s. I had cleared the virus after the 6-month treatment. It was quite heartbreaking to discover it had returned in the 6th month following the end of treatment, and contributed to a period where I lost about a year of my studies – or of much of anything really – to that vague funk that accompanies interferon treatment, along with the distress of the unsuccessful aftermath that I found hard to take and the source of quite crippling anxiety.

Any description of the treatments I've been offered over the years since involved lengthy commitments of up to 12 months, the

possibility of side effects and unsatisfying cure rates, particularly for my genotype. I had already lost time and was not keen to lose more, to give up time that could be spent on my post-grad studies, or later the projects I was working on such as Federation Square, later the time for my business I was building; it just didn't seem worth it. I was yet to have a result from biopsy or ultrasound that showed the disease was doing any damage, so I waited. And I am now glad I did for the total time lost to this treatment, the one that worked, would be three trips to the pharmacy and two to the hepatitis clinic.

### 3. For those who are avoiding it

That said, waiting was not so easy. It's a time spent wondering why I couldn't feel comfortable to tell people that I have this dis-

ease, and that's why I hide my toothbrushes away from accidental use by others.

The awkward explanations to new partners, when you aren't exactly sure how much risk you are asking them to take.

The mornings after too many drinks the night before when you wonder if this really was the time that you'd finally done it to yourself, that the next fibroscan would come with bad news.

And so, like most people faced with the fear of bad news, I tried the avoiding it, missing scans and not chasing referrals, hoping my fears away. Finding out that I no longer have anything to avoid, no longer need to worry about some future where my luck runs out really was such a release.

### 4. The last reason...

The last reason I'll give is not really a specific argument against why a person might refuse to take treatment. It's really just to say that the moment when the specialist looked at my results and turned casually saying, yep, you're cured – there was a tone he had like there was never any other possibility – that was one of the most incredible moments of my life. Thirty-three years of carrying this disease with all the strange sense of shame, worry and wondering what might happen into the future evaporated like it never happened. And that's a feeling you really do want.

On reflection it's the lack of drama in this story that's the real point. After so many years the end was so easy and ordinary.

## HFV Ladies Day 2018

Saturday 16th June, 10.30am - 12.30pm  
Our Lady's Church Hall, 49 Nicholson St, Brunswick East

### Tango Dancing & Tapas



Come and join other ladies for a bit of fun and great company! Two left feet...no problem, you'll fit in just fine. Bookings are through TRYBOOKING by 10th June.

[www.trybooking.com/UJTL](http://www.trybooking.com/UJTL)

Strictly limited places COST \$15 per person

Please arrive 15 minutes early. BYO Water.  
Dress: Wear comfortable, casual clothing.  
Please bring flat shoes (or socks) and heels.  
Tango Dancing followed by Tapas!!!



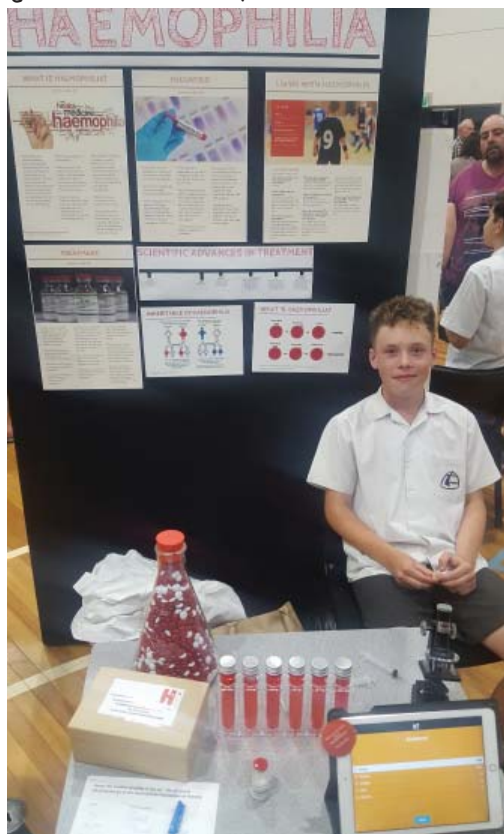
Late last year, HFV was contacted by Isaac, a year 5 student, asking for information on haemophilia to assist with his exhibition.

We sent Isaac an array of information. He came back to us with some questions on what it is like to have haemophilia. One of our young members, Lachie, kindly stepped up and answered all the questions Isaac had.

Here is a photo of Isaac at his exhibition. Not only did Isaac manage to raise awareness and understanding of haemophilia but with the help of his school community he raised \$311!

Those funds will go directly to assist our HFV peer programs so a big thank you to Isaac.

We are always happy to provide information and support to kids and families looking to raise awareness of bleeding disorders in their community. Just gives us a call or drop us a line...



# FUNDRAISING OF BLEEDING

in  
comm

## Dear Friends of Bronwyn Grant,

We recently received a lovely Christmas card from Bronwyn with a cheque for \$1280 and a little note asking us to mention it in our newsletter as Bronwyn likes to show it to you.

Well, what can we say but THANK YOU for the many, many years of support you have shown us through your support of Bronwyn and her efforts in fundraising. We can only imagine you are all amazing people, to year in and year out, support Bronwyn on a shopping trip or Girls Christmas Breakfast. But we also know that Bronwyn is a pretty special kind of person to receive the support that she does!

We thank you all again for your support and hope that you continue to find the time to enjoy each others company and your wonderful friendships at whatever Bronwyn has planned for you!

The HFV team

## THANK YOU

There are many people in our community that support HFV financially through donations at membership renewal time, through fund raisers at their local school or community group, through sausage sizzles or morning teas and cup cake sales, shopping trips or even families requesting donations to us in lieu of birthday gifts!

To all of you THANK YOU, truly and sincerely. Your donations keep our programs running and allow us to CONNECT SUPPORT & EMPOWER!

# & AWARENESS DISORDERS

the  
unity

Hi! Our names are Harrison and Callum Grech and we both have severe Haemophilia A. We are in grade 4 and grade 1 at Hamlyn Banks Primary School in Geelong.

We were very excited that our school participated in a Haemophilia Awareness week in November. Throughout the week all classes spent time learning more about Haemophilia and how it affects boys like us. On Friday 1st December we finished the week off with a dress in red day, where we could all wear red clothes and for a gold coin donation you could get your hair sprayed and/or face painted..... red of course!

It was a great day and we were so happy to see everyone wearing red and eager to learn more and understand our condition. We also both spoke at assembly to the whole school. As a school we raised over \$250.00 towards the Haemophilia Foundation, which we are all so proud of.

We can't wait to do it all again next year!

Harrison and Callum Grech  
(written with mum's help!)





# BREAKTHROUGH IN GENE THERAPY FOR HAEMOPHILIA B

On the 7th December, researchers at Royal Prince Alfred Hospital in Sydney and their international collaborators announced a breakthrough in gene therapy for haemophilia B

In a study of 10 men with haemophilia B who were treated with a single injection of gene therapy, all had a substantial increase in their clotting factor IX (9) levels. As a result of this treatment nearly all had no further bleeding episodes. 8 out of 10 have not used clotting factor replacement therapy since then.

For RPA's Professor John Rasko and the research team from Children's Hospital in Philadelphia, this is the culmination of 20 years' work.

"We are very excited about the results, as those people in our trial have previously had to live with the risks of spontaneous bleeding every day. To prevent potentially life-threatening bleeds they have typically had to inject themselves with clotting factors every few days," said Professor Rasko.

"This trial has targeted haemophilia B, which affects about 500 males in Australia - with about 100 experiencing a severe form of the condition, but our next focus is targeting haemophilia A, which affects more than 2300 people."

Before receiving the experimental gene therapy treatment, clinical trial participant Mark Lee, 38, had

severe haemophilia and clotting factor infusions up to three times a week since birth. Since the gene therapy injection his factor levels are in the normal range and he has not had any bleeds.

"This is life-changing for me. I spent my childhood wrapped up in cotton wool, unable to play football or do any of the things my mates could. I would always remind myself that there were people worse off than me, but it was still disappointing," said Mark Lee. "I have two daughters who are carriers for haemophilia, but now I know that if they have affected children, it will be one injection and they can live normal lives. This goes beyond our little family currently. It will have a positive impact on all generations to come."

Daniel Credazzi, Vice-President of Haemophilia Foundation Australia, who has a son with haemophilia, welcomed the breakthrough, saying: "The real potential of a cure with safe and effective gene therapy is very exciting for people living with this chronic condition, and for their families. My wife and I have been looking forward to this news since our son was diagnosed with haemophilia 13 years ago. We are grateful to all the courageous people who have participated in gene therapy trials."

## STUDY RESULTS

Although this was a small study and has not yet had long-term follow-up, Professor Rasko sees this as a major step in haemophilia treatment. "We now know how to beat the immune response to



Mark Lee and family, Prof John Rasko and Daniel Credazzi



achieve what may be a permanent cure,” he said.

Before the study started, all 10 participants had very low factor levels, below 2%. After treatment their factor levels were sustained at a mean of approximately 30%. Only one participant needed to use factor replacement therapy for bleeds after treatment, but used 91% less factor than before. There were no serious side effects.

The results of the clinical trial were published in today's New England Journal of Medicine.

#### WHERE TO NEXT?

Professor Rasko explained that the success of this small clinical trial can now pave the way for a larger study in haemophilia B with long-term monitoring for at least 15 years to confirm the results. His team at RPA and their collaborators in Philadelphia will also be commencing a similar small experimental clinical trial in haemophilia A in 2018. This forms part of the international work currently underway to investigate gene therapies for haemophilia that are safe and effective.

For people with haemophilia in Australia, these are exciting times, with a range of new ground-breaking haemophilia treatments coming on to the market as well as the first indications of success in these experimental gene therapy treatments. If you have questions about experimental gene therapy or other new haemophilia treatments, talk to your specialist haemophilia doctor (haematologist).

Reprinted from HFA website  
[www.haemophilia.org.au](http://www.haemophilia.org.au)

*Please note, there are currently a number of different trials around the world on gene therapy.*

*Gene therapy offers considerable hope to our community for the future. We do, however, need to be realistic in our expectations.*

*Trials are currently in play. Trials that look promising need to go through extremely rigorous testing and monitoring, for up to 15 years. It is important that we keep ourselves educated on new therapies that are on the horizon but also realistic in our expectations of when our community may see the benefit from these trials/therapies.*

*Our community members should consider the benefits of other treatments available now and in the near future.*

*HFA will be featuring an article on Gene Therapy in their Autumn edition of National Haemophilia (to be published shortly) which should assist in managing our expectations around gene therapy.*

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

**WORLD HEMOPHILIA DAY 2018 | APRIL 17**

**SHARING KNOWLEDGE MAKES US STRONGER**

The global bleeding disorders community is filled with the first-hand knowledge and experience needed to help increase awareness, and improve access to care and treatment.

Find important educational resources and hear from top experts at [elearning.wfh.org](http://elearning.wfh.org)

facebook.com/wfhemophilia

@wfhemophilia  
Comment, tweet, follow and hashtag #WHD2018 to stay social!



# HFV COMMITTEE 2017/18

*Our committee for 2017/18 have already been working hard behind the scenes to ensure much community engagement for this year. Karen, Zev, Leonie and Erika share a bit about themselves and their involvement with HFV. In the next edition, we will hear from Sharron, Donna, Dan and Robyn.*



My name is Karen Donaldson, I am a mother of two active boys Will and Archie, wife to an amazing man who serves as a MICA Paramedic to the Geelong region, and a busy physiotherapist in the area of Women's Health and fitness.

We became involved in the bleeding community when Will was diagnosed with severe Haemophilia A 10 years ago. We received much needed support and education early on after diagnosis but especially when we moved to Victoria from NSW a year later.

My committee contribution includes healthcare experience and knowledge, and the enthusiasm and strong interest in helping organise the annual community camp.

It has been a wonderful experience to be a part of the HFV committee.



I am Zev Fishman. I have 3 adult children and 2 grandchildren. I'm actively working and have severe haemophilia A. I have been actively involved on the committee for a number of years now. My reasons for being involved with HFV is a desire to communicate with people with haemophilia and make all people with bleeding disorders aware of what is available in our community for them. I am involved in running the HFV Men's Retreat which is a very beneficial program and relaxing weekend away from the challenges of everyday life. I am always happy to chat with like-minded people about issues relating to their bleeding disorder.



My name is Leonie Demos. I have been on Committee for some time and my son has Haemophilia. I am committed to working with others at HFV and the broader community to strengthen our connection with those in the HTC as well as allied health services to ensure the best possible health outcomes for our community. Our health care in Victoria is amazing and I enjoy dedicating some of my time to building our capacity to aim for excellence across health and social factors that impact on our families. I enjoy working with others who share this vision.



I'm Erika Mudie. My husband, and fellow committee member, Dan Korn has a bleeding disorder. In the next year, I'd like to help HFV re-assess and elevate it's member engagement. We run great programs and have a great newsletter, but there must be gaps we can also fill. I want us to look at those and see what can be done.

## Royal Children's Hospital

**2018 HAEMOPHILIA TEACHER'S SEMINAR**

HFV was delighted to be able to support the 2018 Royal Children's Hospital Teachers Seminar.

Over 50 kindergarten, primary and secondary school teachers were in attendance to learn about haemophilia from the RCH staff, parents and children with haemophilia.

This event gives the teachers and really good insight and understanding into a condition they are mostly unfamiliar with. Teachers, understandably, can be quite nervous about the prospect of managing a child with haemophilia and maybe unclear of how to deal with a bleeding episode.

Dr Chris Barnes opened the session, offering a clear understanding of what haemophilia is, the impact on the child and family and how haemophilia may impact their schooling.

Nicola Hamilton, physiotherapist, explained about bleeds and effects on muscles and joints in the short and long term.

Janine Furmedge, haemophilia nurse,

explained how to treat a suspected bleed or injury and provided the participants with an information guide specifically for schools to assist in managing children with haemophilia.

This seminar not only increases awareness and understanding of haemophilia in the wider community but it offers reassurance to the family of the child to know that their teachers have a good understanding of how to manage their child's condition.

The highlight for the teachers was the opportunity to speak directly with 3 school age boys about their haemophilia and whether it impacted them at school.

The boys were honest and articulate. They explained what it felt like to have a bleed, what they would do if they did have a bleed, whether they participated in sport or camps, whether they were happy to discuss their haemophilia in class. The teachers were given the opportunity to ask the boys questions about their haemophilia and could also speak to their parents.

The feedback we received from the participants was very positive. The increased level of knowledge alleviated much of the anxiety many of the teachers had previously felt. They understood that the kids are very good at managing their condition and good at advocating for themselves. They understood that physical activity is just as important for a child with haemophilia as anyone else and not to treat kids with haemophilia any differently.

Thanks to the RCH team for all their hard work in running this event.

We would also like to thank the RCH team for producing a very powerful video involving our HFV boys discussing what it is like to have haemophilia. This video was presented at the Red Ball in October and received a hugely positive response.

**Please view this video through our website and please share with the wider community.**

Andrea McColl



In 2018 there will be further development of MyABDR as part of the National Blood Authority Crimson Project. HFA is looking for a few more MyABDR users to join the HFA MyABDR Focus Group to give feedback on the current MyABDR system and proposed changes.

**INTERESTED?**

You would need to be:

- Currently using MyABDR
- Prepared to answer questions via email from time to time in the next 12 months
- Perhaps do some home testing of proposed enhancements.

If you would like to participate, please contact Suzanne at HFA on [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) or 1800 807 173



Over the summer I have been watching some TED Talks ([www.ted.com/talks](http://www.ted.com/talks)). If you are not aware TED is a non-profit devoted to spreading ideas, usually in the form of short, powerful talks that cover almost all topics — from science to business to global issues. It's been a good opportunity for me to try and learn something new... pick a different topic and try and gain a bit of an insight.

A talk that I found fascinating was by Susan Pinker, a Canadian Sociologist, who ran a talk titled "The Secret to living longer may be your social life". She has studied in depth research by Julianne Holt-Lunstad, a researcher who reviewed tens of thousands of middle aged people studying every aspect of their lives, to ascertain

what has the greatest impact on longevity of life.

Fascinatingly, this research placed social connectivity as the highest indicator for longevity of life. Even more fascinating was that it didn't need to be close relationships that had this hugely positive impact (close relationships with at least 3 people was highlighted as very valuable) but interaction with a neighbour, the newsagent, the checkout assistant, a postie... any interaction where you make eye-contact and converse, even just a few words, is enough to increase the cortisol and endorphins and have a hugely positive impact on your health outcomes.

I really recommend taking a bit of time to view this talk. It is certainly

not suggesting for a minute that people should maintain an unhealthy lifestyle but simply highlighting the importance of physical social connectivity may have a huge influence on your health and well-being so maybe next time you are out and about make a bit of an effort to connect with someone, if you are at work take the time to speak to a colleague rather than sending an email. It's free and easy to do!

[www.ted.com/talks/susan\\_pinker\\_the\\_secret\\_to\\_living\\_longer\\_may\\_be\\_your\\_social\\_life](http://www.ted.com/talks/susan_pinker_the_secret_to_living_longer_may_be_your_social_life)

Julia Broadbent



Despite a last minute date change our 'Bring a Buddy' youth event finally took place on Sunday 25th February.

Dialogue in the Dark is a sensory journey set in total darkness - an incredible experience where you step out of your comfort zone and take on the challenges of a bustling, simulated Melbourne in the dark.

Our youth learnt to navigate peak-hour in pitch black and felt their way through a crowded footpath and experienced Melbourne as a person with low vision or blindness would.

This was a great challenge for our youth and an opportunity for them to develop a



greater understanding of the impact of another health related condition.

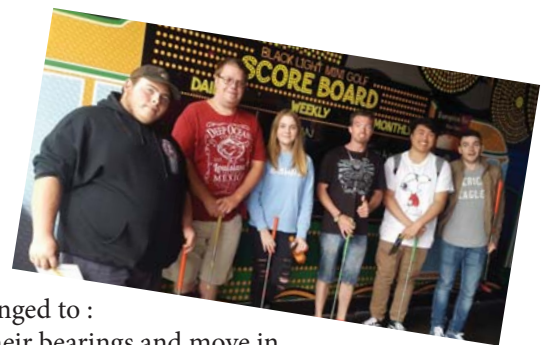
Our youth were challenged to :

- Find their bearings and move in complete darkness
- How to identify the world through a variety of senses
- How to communicate and collaborate with other people, without visual cues

Following Dialogue in the Dark we headed for a bite of lunch and we ended the day with Glow Golf...which was lots of fun!

We'd love to see a few more faces at the next youth event 'ESCAPE ROOM CHALLENGE'. See page 9 for more details!

If you interested in attending Dialogue in the Dark please go to the website [www.dialogueinthedark.com.au](http://www.dialogueinthedark.com.au)



Our annual weekend retreat for the adult male haemophiliacs of HFV (universally shortened to "the Men's Weekend") was a great success again. We eagerly counted down the kilometers towards the rented farmhouse near Carisbrook until we pulled into the now-familiar drive and kept our eyes peeled to see who had made it there ahead of us.

A delicious barbecue Friday evening led directly into a late bull session where we traded personal news as well as info on the new treatments and trials a few of us have started. Those of us who had seen each other at the Community Camp or the fishing trip late last year were happy to

have a chance to catch up with the others who mark the Men's Weekend as their annual chance to join in.

Some good-natured ribbing about who was king (or fool) of the billiards table kept us occupied as we each enjoyed massage therapy and meditation sessions in turn. The top-notch cooking and attentive care from Sharon of Redome rejuvenation treatments capped a great weekend of friendship and fellowship. There were a few beds still unclaimed so we're looking forward to seeing some more new faces next year!

Dan

## 2018 Men's Retreat



## Men's Group Fishing Trip



To be part of any of our peer support groups or be connected with someone who understands your journey, just contact HFV.

We'd also love to hear from you if you have ideas or suggestions for events, good locations, new groups or just a chat!



03 9555 7595



info@hfv.org.au



13 Keith St,  
Hampton East, VIC 3188



BOOK  
NOW!!!

**SUPERHERO**  
**theme**

# 2018 COMMUNITY CAMP

Camp Wilkin ANGLESEA  
27th - 29th April

SUN, SEA, SAND  
& HEAPS OF FUN!



REGISTRATION FORMS ENCLOSED IN THIS EDITION OF 'THE MISSING FACTOR'  
BOOKINGS CAN BE MADE THROUGH TRYBOOKING. [www.trybooking.com/ULSJ](http://www.trybooking.com/ULSJ)

HFV BABY & TODDLER

**G R O U P**

We are trying to establish a baby and toddler group for families with young children.

It will be a very casual get together at the Royal Park Nature Play Playground next to the Royal Children's Hospital.

The gathering will take place in April or May (we are flexible on dates!) and on Thursday late morning. Janine and Julia from the RCH will try and join us for a short time too.

We already have 2 families keen to attend so if you are interested in also attending, please contact Julia Broadbent at HFV on 9555 7595 or email [julia@hfv.org.au](mailto:julia@hfv.org.au) Please refer to our website for updates.

If you cannot attend the get together due to distance, work or other commitments but would like to connect with other parents with young children with bleeding disorders, please call us as we would love you to be involved in a wider network around Victoria.



# HFV Noticeboard

To post a message on our noticeboard, please email our HFV office at [info@hfv.org.au](mailto:info@hfv.org.au) or call 9555 7595

## YOUR HELP IS NEEDED

The Department of Health and Human Services has developed a short survey (less than 5 minutes) to help prepare for the upcoming influenza season and would appreciate your assistance in both completing the survey and promoting it to your networks (our HFV members).

The aim is to understand how the Victorian public and those who provide healthcare to them currently view flu and annual vaccinations, as well as other protective measures.

The information we obtain through this survey will help us develop a communications campaign to address any knowledge gaps or other barriers to immunisation and ensure everyone understands how to protect themselves and those in their care from this serious disease.

A high number of responses will support a better informed and targeted campaign. Ultimately, this means we'll help save the lives of some of our most vulnerable Victorians. Here's the link:

<http://www.surveygizmo.com/s3/4148691/>

**Seasonal-influenza-survey**

**thefemalefactors**

### WANT TO BE INVOLVED?

We are looking for women affected by haemophilia, VWD or other bleeding disorders.

Tell your story and have it included in the new resources – it can be anonymous if you prefer – and you can write your story yourself or be interviewed over the phone and/or comment on the draft resources.

Contact Suzanne at HFA on [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) or phone 1800 807 173

## HFV STATEMENT OF COMMITMENT TO CHILD SAFETY

### INTRODUCTION

The Committee of Management of Haemophilia Foundation Victoria (HFV) is responsible for overseeing the operations of the organisation and ensuring that the organisation meets its legal and financial obligations. In line with this responsibility, HFV is committed to child safety.

### STATEMENT OF COMMITMENT

- Haemophilia Foundation Victoria is committed to child safety.
- We want children to be safe, happy and empowered. We support and respect all children, as well as our staff and volunteers.
- We are committed to the safety, participation and empowerment of all children.
- We have zero tolerance of child abuse, and all allegations and safety concerns will be treated very seriously and consistently with our robust policies and procedures.
- We have legal and moral obligations to contact authorities when we are worried about a child's safety, which we follow rigorously.
- Our organisation is committed to preventing child abuse and identifying risks early, and removing and reducing these risks.
- Our organisation has robust human resources and recruitment practices for all staff and volunteers.
- Our organisation is committed to regularly training and educating our staff and volunteers on child abuse risks.
- We support and respect all children, as well as our staff and volunteers. We are committed to the cultural safety of Aboriginal children, the cultural safety of children from a culturally and/or linguistically diverse background, and to providing a safe environment for children with a disability.
- We have specific policies, procedures and training in place that support our leadership team, staff and volunteers to achieve these commitments.

If you believe a child is at immediate risk of abuse phone 000.

# diary dates

## MARCH

16 Ladies Day Out

## APRIL

TBC Baby & Toddler Picnic (or May)

27-29 HFV Community Camp

## MAY

19 Bairnsdale Regional Visit

20 Traralgon Regional Visit

20 Warragul Regional Visit

## JUNE

16 Ladies Day Out

TBC Youth Event Escape Room  
(or July)

## AUGUST

10 Wangaratta Regional Visit

11 Shepparton Regional Visit

11 Echuca Regional Visit

12 Bendigo Regional Visit

12 Ballarat Regional Visit

## SEPTEMBER

8 Warrnambool Regional Visit

9 Horsham Regional Visit

9 Ararat Regional Visit

## HAEMOPHILIA TREATMENT 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 Furnedge | Clinical Nurse Consultant  
Julia Ekert | Office Data & Product Manager  
Nicola Hamilton | Physiotherapist  
Wade Wright | Social Worker

### RONALD SAWERS HAEMOPHILIA CENTRE

The Alfred  
1st Floor, Sth Block -William Buckland Centre  
Commercial Road, Melbourne 3004  
P. (03) 9076 2178 E. (03) [haemophilia@alfred.org.au](mailto:haemophilia@alfred.org.au)

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

We are planning a WALK AROUND

## ALBERT PARK LAKE for 2018 BLEEDING DISORDERS AWARENESS WEEK

We would like to make this an annual event and an opportunity for all our members, families including grandparents, aunts and uncles and even friends to join us.

There will be more information to come but pencil Sunday 7th October into your diaries!

# HFV MEMBER SERVICES & PEER SUPPORT

## Membership Annual 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:

- **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.

## Live Well Funding:

Live Well Funding is open to all current financial members who can apply for funding for any activity or one off item that will assist in the management of their conditions such as mobility support aids, meditation, massage etc.

## 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 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

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

Fax: (03) 9555 7375

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

## MEN'S GROUP

Our current group meet for their Annual Men's Retreat – a much needed weekend away that included massages, relaxation and meditation. In 2018 eight members attended the retreat, all promising to return after making powerful connections with their peers. There are also opportunities to meet for brunch and lunch during the year.

## WOMEN'S GROUP

The group meets once a year over lunch and usually get to enjoy an event with a twist. Our most recent event our ladies spent a day at the Peninsula Hot Springs and enjoyed a beautiful meal together.

They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant...to name but a few.

## YOUTH GROUP

The Youth Group aim to meet up a few times a year usually based around an activity like laser skirmish or bowling and then head out for lunch.

We also have our actively involved Youth Leaders who are present at our family camp. They attend specific youth leadership training led by our formally trained youth leaders – an initiative developed by the leaders themselves.

## GRANDPARENTS GROUP

The Grandparents and Friends lunch is a great opportunity to connect with all the grandparents and share the company, stories and experiences so please come along and enjoy the day. Lunch is provided by HFV and the company is always good!

The initial impact of haemophilia can be a traumatic and stressful time in our lives and interaction with other grandparents can be a reassuring and rewarding experience.

## BOYS GROUP

Our Boys Toys Day Out is a wonderful opportunity for our boys to get together with other boys with haemophilia or related bleeding disorders and to spend the day with their dad or another significant male in their lives...grandfathers, uncles or family friend.

Previously our Boys Toys events have included fishing trips, Go-Karting, Laser Tag and Tree Top Adventures.





# REGIONAL VISITS 2018

**11**  
LOCATIONS

<BAIRNSDALE \* TRARALGON \* WARRAGUL>  
<WANGARATTA \* SHEPPARTON \* ECHUCA \* BENDIGO \* BALLARAT>  
<WARRNAMBOOL \* HORSHAM \* ARARAT>

YOU ARE INVITED TO JOIN OUR STAFF AND COMMITTEE MEMBERS  
AT ONE OF OUR 2018 REGIONAL VISITS!

Depending on the time slot HFV will be providing dinner, morning tea or afternoon tea (coffee/cakes/snacks). Once bookings have been made and numbers established HFV will notify you of the venue location.

BOOKINGS ARE ESSENTIAL THROUGH TRYBOOKING [www.trybooking.com/361585](http://www.trybooking.com/361585)

BAIRNSDALE 19/5 6-8PM  
TRARALGON 20/5 10-11.30AM  
WARRAGUL 20/5 2-3.30PM

WANGARATTA 10/8 6-8PM  
SHEPPARTON 11/8 10-11.30AM  
ECHUCA 11/8 2.30-4PM  
BENDIGO 12/8 10-11.30AM  
BALLARAT 12/8 2.30-4PM

WARRNAMBOOL 8/9 6-8PM  
HORSHAM 9/9 10-11.30AM  
ARARAT 9/9 2-3.30PM

MAY

AUG

SEPT