

THE *MISSING* FACTOR

*HELPING OUR TEACHERS
to support our kids*

*Overcoming barriers
to attending camp*

Blood Brothers
hit the mark

connect • support • empower



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*Our Blood Brothers camp really hit the mark in **CONNECTING, SUPPORTING and EMPOWERING** each other*



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Editor: Julia Broadbent



VICE PRESIDENT'S REPORT

Welcome to 2017. I thought it was my turn to step up and give Leonie a hard earned rest. The work she does in front of and behind the scenes is endless.

Since our last edition of The Missing Factor our staff have enjoyed an extended break and returned to HFV well rested and with much enthusiasm.

December was particularly busy starting with our stakeholder dinner which is an important opportunity for us to thank not only those members that have contributed to HFV throughout the year but also those we work with during the year to enable our peer support programs to work so well.

Purple Soup bring such a wealth of experience and understanding in supporting our community, which not only enhances our camps but really builds the confidence of individuals and binds us together as a community. It is only through the collaborative efforts of our treatment centre staff that we are able to connect and engage with 'non' HFV members of our community with the hope that they see the benefits of HFV and join. And through our work with the treatment centre teams we obtain an insight into issues and trends that our community may be facing and can work together to improve outcomes.

The HFA team do such valuable work for our community, advocating on so many different levels, providing resources to our community and supporting HFV programs throughout the year. Our 'stakeholders' are so important to us and it is important for us to reflect on all that we have and will continue to achieve for our community working in this strong collaborative manner. So again, we thank all our stakeholders for their commitment to HFV.

Our Blood Brothers headed off on the 9th December for their 5th camp. The camp focuses on skills such as independence, resilience, mentoring and self-advocacy. We were again so grateful to the staff at both treatment centres for taking time out of their weekend to attend the camp and provide valuable education sessions for the participants. This casual (non-clinical) setting is the perfect forum for the youth to hear the messages of their health care providers.

We were again pleased to support the RCH Teachers Seminar this year. Nearly 60 staff from schools based all over Victoria were present. We can easily forget how daunting the prospect of a student with haemophilia could be for teachers who are not familiar with the condition. It is rewarding to know what a positive impact the teachers seminar

has on these staff and ultimately comforting to know as parents that our children are in safe and competent hands whilst at school.

I am pleased to say our Men's Retreat was another great success. Our eleven attendees were treated to a relaxing weekend away which included a massage, relaxation, meditation, plenty of food and a couple of late nights! We'd love to hear from more men in our community about what their needs are so we can support you throughout the year – not only at an annual retreat.

Don't forget we have our Grandparents lunch coming up this month so if you haven't been before please book in. These are lovely people just looking to connect with other grandparents and friends in our community...treat yourself to a complimentary meal and I'm sure you will really enjoy the company.

Community Camp, previously known as Family Camp, is coming up in April and I'm very excited that it is in Anglesea...nearer to my neck of the woods this year! We have a brilliant program planned and we know it is going to be a very special camp this year so please come along and join us. As the name suggests this camp is for our ALL our community so come along and see what it is all about.



We have also decided to hold our next regional visit during the Community Camp. It seems like the perfect opportunity for us to connect with the wider community that may be down in the South West of Victoria so please join us for lunch on Sunday 30th April, just call the office to book in. You'll get a taste of what our camp is all about and get to meet many people in our community and we would love to share that with you.

I'm delighted that the theme for this year's World Haemophilia Day is 'Hear their Voices' - shining a spotlight on the millions of women and girls affected by bleeding disorders. It's a topic close to my heart and I think it is a timely reminder to step up, be heard and advocate for ourselves strongly.

Our Red Ball is coming up in October and we are looking for suitable 'high end' donations for the silent auction. If you have any suitable items that would appeal to corporate sponsor or you have connections that may be able to assist, please contact the office.

I hope to see you all at one or many of our fabulous events this year. Remember, we are just on the other end of the phone or email if you ever need anything.

Sharron Inglis
Vice President - HFV

ALCOHOL AND DRUGS ...dependence and addiction

It is often difficult for people to recognise that they have become dependent on or addicted to alcohol or drugs. They may see it as a temporary situation because they are in physical pain or because they are dealing with grief or loss. Recognising there is a problem is the first step to dealing with a dependence or addiction.

Asking for help when you first suspect you have a problem is important so that you can get support to make changes early. If you think you have an addiction, speak to your local doctor or call DirectLine on 1800 888 236 as soon as possible.

Difference between dependence and addiction

Becoming dependent on alcohol or drugs means you rely on a substance to feel good or to cope with everyday life. Your body adapts to it, needing more and more of it to get the same effect (called tolerance). Your body develops specific physical or mental symptoms if you stop using the substance abruptly (called withdrawal). This can happen with many types of drugs when they are used for a long time – even prescription medication.

Just because you are physically dependent on alcohol or a drug, it doesn't necessarily mean you are addicted, but often the two go together.

People who are addicted to alcohol or other drugs continue to use it despite the harmful consequences. They find it difficult to stop using, which can often significantly impact and disrupt their lives – failure to meet work, social or family obligations, as well as health problems.

Sometimes, it can be hard to tell the difference between dependence and addiction. With prescription medication, a person may need more and more because their medical problem is getting worse, or because their body is becoming used to the medication, so its effect is lessened. This is sometimes categorised as dependence rather than addiction.

Early stages of dependence and addiction

Many alcohol and drug addictions start with experimental use in social situations and often at a young age. Some drugs have a higher risk associated with their use and cause dependency more quickly than others.

Some signs that you may have an alcohol or drug problem are:

- changed eating or sleeping habits
- caring less about your appearance
- spending more time with people who drink excessively or use drugs

- missing appointments, classes or work commitments
- losing interest in activities that you used to love
- getting in trouble in school, at work or with the law
- getting into more arguments with family and friends
- friends or family asking you if you have a substance abuse problem
- relying on drugs or alcohol to have fun or relax
- having blackouts
- drinking or using drugs when you are alone
- keeping secrets from friends or family
- finding you need more and more of the substance to get the same feeling.

Often it is family and friends who first recognise that a person they care about has an alcohol or drug problem. They may have noticed them acting differently – being withdrawn, always tired, increasingly hostile or easily upset. They may ask the person straight out if they have a problem.

If that happens to you, listening to what they have to say and asking yourself if they are right is a positive first step.

Recognising an alcohol and drug problem

There is no particular type of person who becomes addicted to alcohol or drugs. It can happen to anyone.

What starts as occasional use of a drug or one prescription of pain-relieving medication, for example, can get out of control as time passes. You may find you need bigger doses to get the same feeling or to lessen the pain. Eventually, you may depend on the drug to feel good or to get through your day.

Other signs that you are becoming addicted to alcohol or drugs include:

- having intense urges for the substance – this could be once a day or several times a day
- needing more of a substance to get the same effect
- fixating about making sure you have a constant supply of the substance
- spending money on the substance, even when you cannot afford it
- cutting back on social or other activities
- not meeting your work, family or study responsibilities

- lying to people about your alcohol or drug use when they ask
- doing illegal things so you can get the substance, such as stealing
- taking risks such as driving when you are under the influence of the substance
- trying but failing to stop using the substance
- experiencing withdrawal symptoms when you try to stop taking the substance.

Quitting alcohol or drugs

Quitting alcohol or drugs is hard to do because repeated alcohol or drug use makes the body more dependent and changes the brain. Brain scans of people who have an addiction often show changes in the areas of the brain that help you learn and remember, make good decisions and control yourself.

For this reason, many people find they cannot stop by themselves. The best thing you can do is to talk to someone you trust so you do not have to deal with your problem alone.

Getting help for alcohol or drug dependence or addiction

If you think that you or someone close to you has a drug or alcohol problem, speak first with your local doctor or call DirectLine on 1800 888 236. DirectLine is a 24-hour-a-day information and advice line that is free, anonymous and confidential. You can talk to a professional counsellor who is experienced in alcohol and drug-related matters, and they can start you on the right track to recovery.

Where to get help

Your doctor
DirectLine, call 1800 888 236
Youth Drug and Alcohol Advice (YoDAA) line, call 1800 458 685.



BLOOD BROTHERS

CONNECT SUPPORT EMPOWER

The 2016 Blood Brothers Camp was from 9th - 11th December and held at The Briars, Mount Martha. HFV was successful in securing sponsorship from CMV Staff Charitable Foundation to assist youth from South Australia to attend. South Australia and Tasmania do not currently have a Foundation operating, and so HFV invited youth from those states to attend the camp.

The Blood Brothers Camp, run by Purple Soup, was an incredible experience that has helped me feel more connected to the haemophilia community. As someone with haemophilia in South Australia there is no state organisation for the community so the first time I met anyone else with haemophilia from SA was at the Australia and New Zealand Convention in Queensland.

Getting the opportunity to be flown over to Victoria to be a part of the blood brothers camp was a chance I would not refuse.

The camp itself was a fantastic experience that was filled with so many great activities such as laser skirmish, archery, giant swings and a leap of faith but what made this camp such a memorable experience was the ideas behind each of these activities. Each activity had it's own 'lesson' which allowed us a group to share our individual goals that we are hoping to achieve for ourselves but also to help refine and focus them.

The leap of faith, for example, was an excellent team bonding exercise that had the group on the ground holding the rope harness for the climber so that when the person made the jump we would make sure to catch them, and to also be there to share our encouragement to the people that were worried about the jump.

Whilst these physical activities were excellent and fun the part that made this camp great was the ability to have a sense of belonging. For me the best parts were not these physical activities but the mo-

ments before and after when we would be sharing our stories and goals of what we want to achieve. These moments were when it felt great not needing to discuss haemophilia because we were all in the same boat.

If I had to choose a specific moment that has made

me guaranteed to come back for would be the final day of the camp where we had a bus karaoke sessions singing the top hits of Nicki Minaj and Enrique Iglesias where it was everyone just having a blast.

This camp has given me the opportunity to feel apart of a community that has been missing in my life since I was diagnosed with haemophilia and am grateful for the opportunity to attend this camp.

Nathan



HFV would like to thank CMV Staff Charitable Foundation for their support in sponsoring Nathan's attendance at the Blood Brothers camp.



This Haemophilia camp was the first ever haemophilia camp that I have been on.

I am a very quiet person when it comes to meeting new people and making new friends, especially ones who live hundreds of kilometres away from me.

When I got to the Haemophilia headquarters it was quite scary, however the boys and the Purple Soup Team welcomed me in with open arms.

During the camp, the activities were fun and exciting; the night time canoeing was probably the greatest part of the experience and everyone just opened up about their lives and feelings.

The Boy's talk with Dr Chris Barnes was a funny and 'very different talk', but he has answered many questions and I would like to thank him for taking a few hours out of his busy schedule to be there with us on the camp.

I would also like to thank the Haemophilia Foundation Victoria for organising such an event and the Purple Soup Team for being there with us which made the camp a hundred times better.

I am pleased to have made some really good friends and look forward to seeing you all next year for sure!

Marc

CHANGE YOUR FUTURE...

HEP C UPDATE

It has been very exciting to hear reports from community members that they are now cured after treatment for hepatitis C with the new Direct Acting Antiviral (DAA) treatments. After so many years of living with HCV and, in some cases, unsuccessful attempts at interferon-based treatment, they are now free of the virus.

WHAT'S STOPPING YOU FROM TREATMENT?

In February 2017 the Kirby Institute estimated that 25,890 people had initiated hepatitis C treatment with the new DAAs during March to September 2016, which is about 11% of the total number of people living with chronic hepatitis C in Australia. The number of people initiating treatment has decreased every month, from 5070 in March 2016 to 2,500 in September 2016.¹

Although you would expect to see a big number of people accessing treatment in the first few months after waiting so long for the new treatments, the steady reduction in treatment numbers has surprised and concerned Australian hepatitis clinicians and hepatitis organisations. With such large numbers of Australians with hepatitis C still untreated and smaller numbers coming forward for treatment, it remains a public health problem.

Deciding to delay hepatitis C treatment until symptoms of liver disease occur is a particular concern, and one that has also been raised in the bleeding disorders community:

- Liver disease with hepatitis C can advance silently and people may not be aware that they are developing advanced liver disease such as cirrhosis or liver cancer
- Treating hepatitis C before you develop cirrhosis usually means a shorter course of treatment and very high success rates
- It can be harder to treat hepatitis C if you have advanced liver disease
- If you develop cirrhosis and have successful treatment, you will still need to have liver health checks regularly to check your liver health and keep an eye out for signs of advancing liver disease or complications that can be managed.

As you can see in the personal stories of hepatitis C treatment published in National Haemophilia over the last year, people with bleeding disorders and

hepatitis C who have cirrhosis have been treated successfully and painlessly for their hepatitis C with the new DAAs. Nevertheless, having the opportunity to cure their hepatitis C before they developed cirrhosis would have been preferable.

David, who told his hepatitis C treatment story in the June 2016 National Haemophilia, explained that he was not diagnosed with hepatitis C until 20 to 30 years after he acquired it, by which time he already had cirrhosis. If he had known earlier, he would have tried treatment much earlier. Others had tried the old interferon treatments but they were unsuccessful and they have spent years worrying about their liver health while waiting for new treatment options. The very high success rates and few or no side-effects of the new treatments has been revolutionary. David's message about the new treatments is short and to the point: "So if you have hep C, take care of it. Don't wait!"

HFA is keen to ensure that every Australian with a bleeding disorder and hepatitis C has the opportunity to have treatment as soon as possible. However, we are aware that some people experience barriers preventing them from accessing the new treatments.

If you or someone you know have a problem that is stopping you from accessing hepatitis C treatment, we strongly encourage you to talk to your Haemophilia Treatment Centre or your local Foundation or HFA to see what solutions can be found.

WHAT'S NEXT?

As of 1 January 2017 DAA treatments available on the PBS are:

- Harvoni® (sofosbuvir with ledipasvir)
- Sovaldi® (sofosbuvir)
- Daklinza® (daclatasvir)
- Viekira Pak® (ombitasvir, paritaprevir, ritonavir, dasabuvir - tablets with or without ribavirin)
- Zepatier® (grazoprevir with elbasvir).
- Ibavyr® (ribavirin)

Some are used in combination with each other. Some combinations are once-daily tablets.

In November 2016 two new combinations went before the Pharmaceutical Benefits Advisory Committee (PBAC) to be approved for the PBS:

- Technivie® (paritaprevir, ritonavir, ombitasvir) – for the treatment of HCV genotype 4
- Epclusa® (velpatasvir, sofosbuvir – with or without ribavirin) – for the treatment of HCV genotypes 1-6.

PBAC recommended that both Technivie and Epclusa go to the Australian Government Minister for Health, who will consider pricing matters, negotiate with the pharmaceutical companies and make a decision about funding the new medications to go on the PBS.

Increasingly the focus of new treatment development has been on higher cure rates (90-100%), minimal or no side-effects, simple treatment regimens (eg, once-daily tablets), and increasing the range of treatments so that there are treatment options for the variety of genotypes and for those who have had unsuccessful treatment with other DAAs. Clinical trials have considered safety and effectiveness in people with cirrhosis, HIV/HCV co-infection and kidney disease. Some, such as Harvoni and Zepatier, have also been trialled in people with bleeding disorders, showing high cure rates, good safety, few side effects and did not affect bleeding disorder-related bleeding or management of the underlying bleeding disorder.^{2,3} More treatments are currently in the pipeline.

The Australian Government has committed to eliminating hepatitis C in Australia by 2026. We would like to achieve this much earlier in the bleeding disorders community. With the range and success of the new treatments available, this is finally looking like a target we can reach.

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Suzanne O'Callaghan,
HFA Policy Research and Education Manager



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CONNECTING OUR COMMUNITY



Last year the HFV team were delighted to have the opportunity to work with Matt Powell from Straight Arrows to assist with Matt's Road Trip Weekend Away project. This was to engage with men with both HIV and haemophilia. Matt was successful in contacting many of those men in our community and we had very positive feedback from those who attended the 'Road Trip' weekend.

We are very pleased that this group have since met up, along with their partners, for a pre-Christmas lunch.

Again this was a great opportunity for peer support - to connect with others who have faced a similar journey.

We are delighted that Matt is now a HFV committee member and look forward to supporting these valuable peer support project in the future.

Reflections on **WOMEN'S HEALTH**

The Burden of Symptoms

Jane Portnoy - Haemophilia Social Worker
Ronald Sawers Haemophilia Treatment Centre

I've spoken to quite a few women who are mothers and carriers and they are only just becoming aware of the burden of their symptoms. Their experience has not been validated, even the use of the term "carrier" implied that they do not have the condition. When in fact their stories are of heavy periods and issues with bleeding. Of course these are different and not so life threatening or potentially crippling but they do have a major impact of lifestyle, quality of life, self-esteem, and general health. I think the women have not felt legitimate in talking about their own issues, particularly if they are mothers' of boys with Haemophilia, because these boys issues were so much more severe I also think because it falls into the "women's issues" i.e. periods, having children etc.. that it is not comfortably talked about with others, even other family members or doctors. It's essential that women have a GP involved in their healthcare.

Mothers are strong advocates.... except

Julia Broadbent - Communications Coordinator
Haemophilia Foundation Victoria

Some of the strongest advocates for health and wellbeing that I have met in our community are mothers. Mothers of children with bleeding disorders are particularly strong advocates as they step into this advocacy role very early on in their child's life. Mothers are often meticulous at monitoring all aspects of their children's health. If there are any concerns or issues with their child's health or treatment, mothers will consult with healthcare providers without hesitation.

So why does our ability to advocate to the same degree fail when it is for ourselves? How many times have we, as mothers and women, dismissed something health related? We are definitely time poor, striving to be good mothers, partners, daughters, sisters and friends. We are trying to create a good work life balance often with the added complication of health issues. But we tend to put our needs last.

If our health is compromised we are not in the best position to advocate for our families so let's take the time to put ourselves first, review our physical and mental health and take steps towards advocating

Where to go for help? Your GP. Your GP will be able to assess you and manage your needs well. If required your GP can refer you on to the Haemophilia Treatment Centre. You are welcome to call the Ronald Sawers Haemophilia Centre and talk to one of the staff for advice, phone 9076 2179
Other resources: The Female Factors is a wonderful resource, produced by HFA and recommended by the Ronald Sawers Haemophilia Treatment Centre and is available for download on our website under RESOURCES.

effectively for ourselves. We have the skills to do it so let's make some positive changes for the future.

Women in our community that we have spoken to within our peer support groups often talk of the added burden of bleeding issues, particularly heavy periods. Many of these women do not have a diagnosis and some have never discussed their bleeding issues with any healthcare professional. Often women look to their mothers, aunts and sisters to assess if they have 'normal' periods. The issue with this is that often bleeding issues run in families. 'My mother had heavy periods too' just means she probably would have benefited from being assessed by a doctor.

Women in our community have suffered in silence for too long and now it is time for us to advocate for ourselves and our daughters. We need to be talking about these issues in our community, remove the barriers and understand how to go about advocating for ourselves better.

Maintaining a healthy body, physically and mentally will have a positive impact on the whole family and provide children with excellent role models around self-advocacy.



HELPING OUR TEACHERS

to support our kids

Julia Broadbent & Andrea McColl - HFV

The annual Teachers Seminar has just been held at the Royal Children's Hospital. HFV is delighted to work with the RCH team in helping to organise this event as it gives us an insight into concerns and anxieties some teachers face with the prospect of a child with severe haemophilia attending their class or school camp.

As we surround ourselves in all things haemophilia it is easy to forget that it can be quite daunting for teacher who are unfamiliar with the condition.

We often speak to the teachers as they book in to the session and hear many of their concerns. Ideally they would like to send all their staff to the session, which is of course not practical. The message we try to relay back to the teachers is that usually the child can advocate well for themselves and will let the teachers know if they suspect a bleed. Parents will also be an important resource for the school. Sending one or two staff to the session will be adequate and that those teachers can very capably share the information with their colleagues. They will be reassured and confident in the management of the child.

Nicola Hamilton, RCH Haemophilia Physiotherapist shared 4 key points for teachers to share:

- 1. Boys with haemophilia can safely play sport**
- 2. Not every bump will lead to a bleed**
- 3. Sport is a positive and essential part of haemophilia management**
- 4. Listen to the boys - they know their own bodies and can tell you if there is an issue**

One of the components of the seminar is a Q and A session. This is particularly valuable as teachers have the opportunity to ask boys with haemophilia and their parent's questions about their experiences.

Here are some examples of the questions asked and answered:

What age do children get ports?

The age can vary as every child's situation is different but many children with severe haemophilia will have a port fitted by the age of 1 or 2. Ports are mostly removed by early primary school but sometimes needed for longer.

Do we need to know whether the child has haemophilia A or B?

No, the protocol to follow would remain the same for school whether the child has haemophilia A or B. It is very important for hospitals and those treating the child to know if the haemophilia is A or B so the correct clotting factor is given when needed.

Can boys with haemophilia play sports safely?

Yes, children with haemophilia can play sports safely, in fact it is very important for their overall health and wellbeing. There maybe some sports that parents may decide they don't want their child to participate in or may decide to withdraw them when the level becomes very physical such as AFL or if the child has a problem joint. This is a decision for the family often in consultation with the haemophilia team. Boys with haemophilia play many sports including karate, soccer, swimming, tennis, cycling... the list goes on. There is no issue with boys participating in school sports days...their treatment will be administered accordingly prior to the event to prevent any bleeds.

How do children with haemophilia receive their factor?

Children receive their treatment through either infusion into their ports or an injection into a vein - usually their arm. This will usually be done 2-3 times a week. This increases the levels of factor in the child's blood in order to prevent bleeds.

How do you manage your treatment at school camp?

That would depend on a number of things including the length of the camp and the comfort levels of the child, parents and staff. If the child is young it may be that the parent may wish to attend camp as a parent helper as treatment may need to be administered or the parent may choose to attend for just a morning to administer the treatment. Many older children can self administer their treatment and are more than willing and able to do so. The haemophilia centre encourages children to work towards self administration by the time they begin school.

Have you ever had a bleed at school and did it worry you?

Yes, all the boys had had bleeds at school and it didn't worry them, they just let the teacher know

How do you know if you are having a bleed?

The area where the bleed is feels warm and as it progresses can start to swell and feel uncomfortable.

Have you ever had a spontaneous bleed at school?

Yes, one bleed - but it is very rare because we are usually on preventative treatment so is unlikely to happen.

As parents, what message would you like school to hear?

Please treat our children as normal - they are not 'special', just err on the side of caution

THE FACE OF INHIBITORS

Patients, families and caregivers share their stories from around the globe

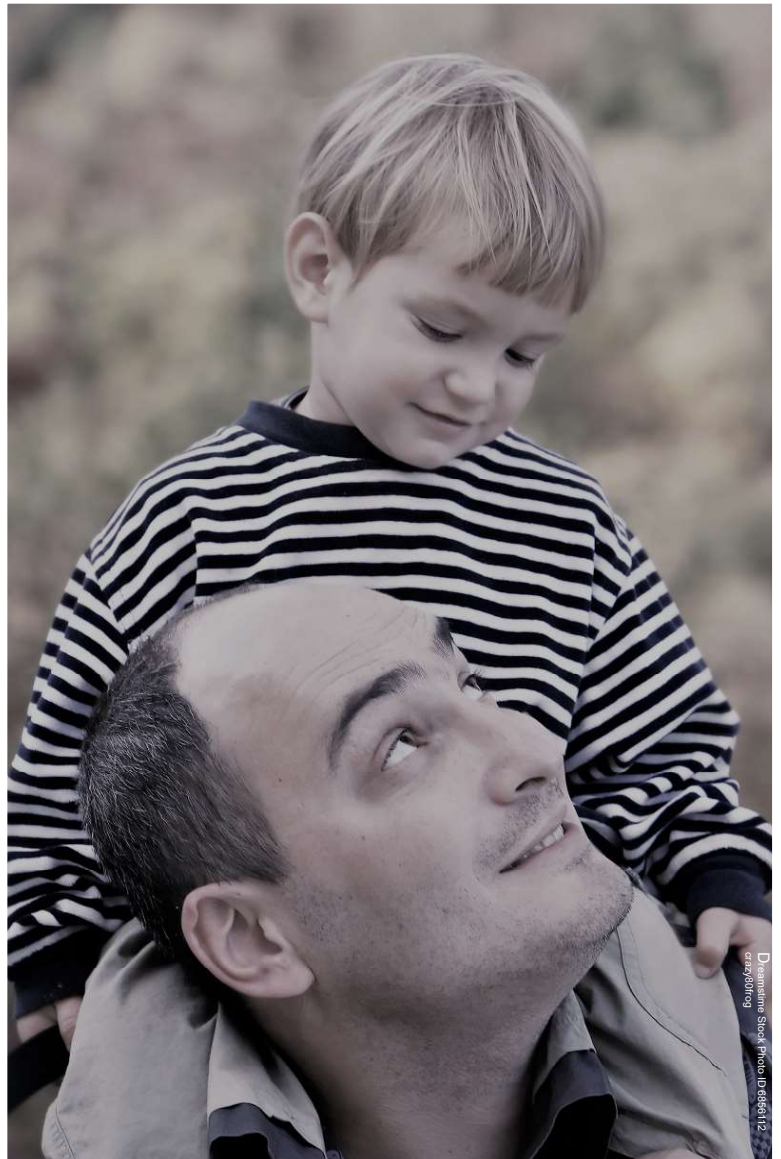
Inhibitors affect between 20 and 40 percent of people with severe hemophilia A. During the WFH 2016 World Congress, patients, families, and caregivers impacted by this rare condition participated in a panel discussion that put a face on their trials and triumphs.

Kari Atkinson, with her 13-year-old son Beau by her side, gave a moving presentation on what life has been like for her, Beau, her husband Craig, and their daughter Jordan since Beau was diagnosed with hemophilia and an inhibitor.

When Beau was only 6 months old, he was diagnosed with severe hemophilia A. Kari and Craig were shocked because there was no known history of hemophilia in their family. However, they had no idea things were about to get worse.

When Beau had a routine blood test at 18 months old, the doctors discovered an inhibitor. “That inhibitor detection literally rocked our world,” Kari said. “It is so different from normal hemophilia. We prayed every night that we could just have normal hemophilia.”

Beau’s inhibitor affects the whole family, Kari explained. “For anyone in this room, you know the number of tears and sleepless nights.” The inhibitor initially had a low titer, and the first treatment proved effective for four years. When it was no longer effective, the next treatment could only be used for a year. Since 2012, Beau, his family, and his caregivers have been struggling with managing his inhibitor



trying different factor treatments and twice inserting ports.

“The cost of care went from \$250,000 (USD) annually with hemophilia to \$1 million to \$1.5 million per year with the inhibitor, depending on the number of bleeds,” Kari said.

Managing Beau’s hemophilia and inhibitor is a true family commitment, Kari stated. “We have to be on high alert at all times. [When a bleed occurs], minutes is our reality between walking, crutches and a wheelchair. It doesn’t matter if we’re in the car, at the amusement park—we infuse.”

At school, Beau stands at the back of the line so he won't be jostled. He can't participate in recess activities. But his friends are very supportive. "Other inhibitor patients are like a family beyond a family," Kari said.

"It takes a village to raise a child with hemophilia and an even larger village to raise a child with an inhibitor."

But there are plenty of positives, Kari said, as Beau smiled beside her. Beau currently receives immune tolerance induction treatment every other day with an extended half-life factor. His inhibitor levels initially spiked, but now they are steady.

Augustus Nedzinkas, a 29-year-old Lithuanian, was diagnosed with hemophilia A with an inhibitor when he was 14 months old. Hemophilia treatment was rudimentary in Lithuania at the time, and, "Sometimes the bleeding wouldn't stop until the joint had expanded to the max," he said.

Nevertheless, he was still able to attend public school, graduate from university, get a full-time job, and even scuba dive.

Augustus had low inhibitor levels for several years, so in 2012, his doctors decided to try a high-dose immune tolerance treatment of 100 IU/kg twice daily. This type of treatment had never been used before in Lithuania, but it was a success. Augustus' inhibitor dropped below zero in the first month.

"Then they prescribed daily prophylaxis and that made my life very happy," he said. "The first thing I did was go spear fishing and get my trophy fish. I changed my car's gear box from an automatic to a manual. And I got married." He has a knee replacement scheduled for next year. "Now I can plan things and expect my health won't be an issue—all I have to do is infuse myself every morning," he said.

Kuixing Li, a nurse at Peking Union Medical College Hospital in China, talked about inhibitors from a caregiver's standpoint.

One of her patients was a 9-year-old boy with an inhibitor. "He was in a wheelchair, and he often lost his temper and was always angry," Kuixing said. "Sometimes he wanted to give up his treatment." His family couldn't afford factor and had to use prothrombin complex concentrates (PCC) instead.

The boy eventually left the hospital after suffering a brain bleed. One day, Kuixing called his grand-

mother to see how he was doing.

"This is not a good story," she said, her voice breaking. "I found out he died—they could not stop his bleeding."

This is not an unusual occurrence in China, which is home to an estimated 100,000 to 150,000 people with hemophilia. "Sometimes I think if the WFH wants to establish their goal of Treatment for All, they should move their office to China," Kuixing said with a laugh.

In 2015, there were only 31 hemophilia treatment centres throughout China—but that's a notable increase from the six centres in 2007. There are also only about 20,000 patients in the national registry.

After a national program from 2008 to 2011 to screen people with hemophilia for inhibitors, Kuixing said the Chinese developed an inhibitor management plan that includes PCC infusion after bleeding and low-dose prophylaxis. It works for about 50 percent of patients, she said. Meanwhile, Chinese chat rooms are full of inhibitor patients who can't afford factor treatment, so they opt for dangerously high doses of PCC.

"It's a big challenge for caregivers to give good care for hemophilia patients in China," Kuixing said.

Reprinted with permission from World Federation Hemophilia

NOT YET BEEN TO OUR HFV CAMP?

Three of our families have shared some of the barriers they had faced before attend their first camp and some of the benefits they experienced...

We asked:

- Were there any barriers or hurdles preventing you from attending the camp?
- Why did you decide to attend your first camp?
- Did you and your family have a good experience at camp?
- What would you say to new families considering attending our camp?



For us the camp was quite a long way away and travelling in the car with a 4 year old and 1 1/2 year old is not the most fun! I guess any other barriers might be that we had young kids and we were concerned that the camp would be aimed at families with primary aged kids and that we may not be able to participate.

Ever since diagnosis 4 years ago in Perth everyone in the community be it doctors, nurses, parents, kids have stressed how good the camps were. We have always believed we would get to a camp as soon as we could. The reason would be that there are some things we can support Kelly with, but seeing other kids live confidently and happily with haemophilia is something that cannot be shown through a book. Further to that, meeting other parents who understand the struggle are essential to our support network.

Yes we did have a good experience and we'll be

back. It was probably our hardest camp (I only imagine it will be easier in the future) because of the age of the kids. We felt really supported with lots of people offering to look after the boys so we could participate and everyone was really encouraging towards the kids. The benefits are the connections you make with other families. These connections are fostered by the types of activities you do (run by purple soup). Unequivocally the best benefit is the small but important experiences that Kelly had, that showed him that haemophilia is a shared condition.

Waiting for the perfect time to jump in and go to one of these camps may not ever present itself, so the time to go is now. The first one might be hard - but think of the second one and the fifth one! Think of all the moments when your kid with haemophilia learns something new or tries something new. The benefits certainly outweigh the fear of the unknown. You are encouraged to participate but not pressured to do so. You can definitely do your own thing, especially

if your kids are little and don't want to adhere to the camp schedule! The camp is a unique experience, there's no better way to support our children with haemophilia and their families.

Tara

For our family the camp was a bit daunting initially. We didn't know anyone else and weren't aware of the benefits.

Our son was feeling like he was the only person in the world with haemophilia. He was around 9 and we thought the camp would be good for him to meet others with the same condition.

Our son loved the camp and is very keen to continue going to camps. We also enjoyed meeting other families and attending the sessions.

We'd say to new families "Give it a go!" You will be pleasantly surprised. It feels good to be amongst others who have similar issues. The kids get so much out of the activities and interactions and so will you.

Debbie

We felt it was too daunting and Grant wasn't too keen as he was in the "we don't need to go to a camp to do things" head space. I think he wasn't quite ready to share our experience back then (which can be a guy thing). Only after attending a ladies day out did I feel reassured to take the step of attending our first camp. We were a little different from most families as Adam did have some balance issues at the time and I was concerned he might hurt himself as we were going through the whole inhibitor thing. I also did not know much about HFV at the time and the wonderful support HFV gives. It would be great to give families an insight with a personal touch as anything in writing such as brochures misses that bit. I think having the camp in your face in the newsletters with families who have attended sharing their stories is good to help show how great the camps are and the benefits of participating.

We decided to attend our first camp as I wanted to meet other families with haemophilia, needed some support, thought it would be fun and it was close to home. I wanted to meet other families and have Adam and Emma see other kids with Haemophilia. As I took the main role as Adam's carer which can be a mum thing, I wanted Grant to meet other dads

and share his experience. I wanted to see if the camp was a worthwhile thing to do.

My first camp was a bit mixed experience as we all were fairly stressed and Adam became tired very quickly over the uneven ground. We however did have a good experience as we came back for other camps. Adam and Emma didn't mix too much at the first camp but on the second one they were used to Purple Soup and knew many of the kids. I think I got the most out of it by sharing experiences with Fiona and Caroline. The first camp left a lasting impression on Adam as he met Scott and Levi, and Adam said to me that cool kids can have Haemophilia. After talking to Levi and Scott he found out that he could still do lots of things he wanted to do, and he looked up to them after that. This was a turning point for us with Adam.

For any new families thinking about attending camp I'd say GIVE IT A GO, the camps are great, every member of your family will get something positive out of it. No matter how difficult you might think it will be to attend we are all there to support you and we are all a big Haemophilia/Bleeding disorder family there to help each other. We can always put you in touch with a family who has recently attended our camp if you would like a chat first before committing...just give the office a call.

Donna

BOOK NOW!!!

HFV

Family Community Camp

Camp Wilken

ANGLESEA

28th-30th April 2017

Registration forms included in the magazine and are available on www.hfv.org.au in resources



Every April 17 **World Haemophilia Day** is recognised worldwide to increase awareness of haemophilia and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH) which chose to bring the community together on April 17 in honour of WFH founder Frank Schnabel's birthday.

In 2017 the theme is **HEAR THEIR VOICES.**

On World Haemophilia Day let's come together to show our support for the millions of women and girls affected by bleeding disorders.

HFA will celebrate World Haemophilia Day with the launch of new The Female Factors resources.

LIGHT IT UP RED!

Landmarks and monuments in Australia and around the world will support **World Haemophilia Day** by changing their lighting red on April 17.

Australia has secured support from landmarks and monuments in each State/Territory to light up red on April 17

Victoria - AAMI Stadium

ACT - Telstra Tower

NSW - Sydney Cricket Ground

South Australia - Adelaide Oval, Riverbank lighting

Queensland - Story Bridge, Suncorp Stadium

Northern Territory - Darwin Convention Centre

Western Australia - Council House, Trafalgar Bridge, Perth Bell Tower

Tasmania - Kennedy Lane Hobart, Railway Roundabout Hobart, Elizabeth Mall Hobart

Show your support on the night, and post photos on our Facebook page of you and your friends at the landmark. #WHD2017

Keep an eye on our website and Facebook page for information on events and happenings.

There will be special activities for our online community, so be sure to follow these pages for details on **World Haemophilia Day** news and activities:

- WFH World Haemophilia Day – www.wfh.org/whd
- WFH Facebook www.facebook.com/wfhemophilia
- HFA's Facebook page - www.facebook.com/HaemophiliaFoundationAustralia.

HOW DO YOU WEAR A RED TIE?

CHALLENGE

haemophilia.org.au/redtie

The RED TIE CHALLENGE was created by the National Hemophilia Foundation (NHF) in the United States. NHF selected a Red Tie to symbolize the blood ties that bind our community. Based on the success of NHF, and with their agreement HFA will launch its own Red Tie Challenge in 2017.

How do I participate?

1. Wear a Red Tie or Red Scarf (you can download one online from www.haemophilia.org.au/redtie)
2. Get your friends, colleagues and social friends on board
3. Record your look on HFA Facebook or Twitter with hashtag #RedTieChallengeAUS
4. Change your profile picture and/or page banner on Facebook in support of the Red Tie Challenge.
5. Make a donation at www.haemophilia.org.au
6. Be creative and have fun!

For resources and more information visit www.haemophilia.org.au/redtie

HAEMOPHILIA
FOUNDATION
AUSTRALIA



HOW DO YOU WEAR A RED TIE?

CHALLENGE

haemophilia.org.au/redtie

PREPARING FOR YOUR TRAVELS

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Creative CommonsStockPhotos

Even if you haven't had a bleed for years, being prepared when you travel can help ensure that your trip is memorable for all the right reasons. Here are some tips on what you should do to plan a successful trip:

be travelling. This way you can check if they have any special requirements for carrying medications and administration kits through their border control. For example, specific documentation or permits may be required when taking medications into some countries.

- **Make sure you know how to manage your haemophilia independently.** Once you are away from home, you won't have your usual support networks to help you manage your condition. This means making sure you know how to reconstitute your medication and give yourself infusions. You also need to know exactly how much medication to inject if you take regular infusions, and how much extra medication you might need to administer if you have a bleed. Finally, you will need to know what to do if you have a bleed that persists after treatment.
- **Arrange for your Haemophilia Treatment Centre to provide you with a Travel Letter.** This is a letter from your physician outlining your bleeding disorder, how this is managed and the contact details of your Haemophilia Treatment Centre in the event of an emergency. Your Travel Letter can be provided to any physicians you may need to see while travelling and will also enable airport security officials to verify that your medication and administration kit are allowed on board. You may also want to get this letter translated into the language of the country you are travelling to if English is not widely spoken.
- **Contact your airline ahead of time.** This way you can notify them that you will be bringing your medication and administration kit on board with you. They will let you know whether they have any specific regulations that you need to follow.
- **Contact the consulate of the country where you will be travelling.** This way you can check if they have any special requirements for carrying medications and administration kits through their border control. For example, specific documentation or permits may be required when taking medications into some countries.
- **Arrange health insurance.** This is an absolute necessity when travelling overseas, regardless of whether the Australian Government has a Reciprocal Health Care Agreement with the country you are travelling to. It is important to ensure that you declare all pre-existing conditions when applying for travel insurance and you may like to consider adding Evacuation Cover. There are a number of companies who provide travel insurance for people with pre-existing conditions such as haemophilia. For more information on travel insurance in general, visit www.smarttraveller.gov.au/tips/insurance.html. For information on specific policies, you can search online or speak to your Haemophilia Treatment Centre.
- **Arrange for any necessary immunisations.** Your Haemophilia Treatment Centre should be able to tell you what immunisations are required when travelling to different regions of the world. You can also visit www.smarttraveller.gov.au/tips/health.html for further information.
- **If you are getting ready to go off and see the world, or just take a trip up the coast, make sure you let your Haemophilia Treatment Centre know well in advance.** They can assist you in making all the necessary preparations to help ensure that you have as safe a trip as possible.

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www.haemophiliahealth.com.au

CAR PARKING AT THE ALFRED & AROUND THE HTC

As we start 2017, it's timely to think about attending your HTC appointment and your mode of travel. The Alfred Hospital is undergoing varying renovations and I'm unable to advise how long the process will take before things return to order. One of the losses has been the disabled parking zones have had to be repurposed or are no longer free. The number of disabled parking marked bays in the Alfred centre car park has been increased to some degree.

The changes include the following:

- beside the William Buckland Building housing the HTC (behind Centre Block) held the most metred disabled parking bays is now the ambulance Zone;
- under the William Buckland Building, which previously had 2 hours free is now a metered zone at \$9.00 for an hour or \$10.00 for a day. These bays are at a premium due to the long treatment programs of other patients of the building.



Patients and visitors



Changes to disabled parking from 26 November 2016

New car parking arrangements will make more disabled spaces available in areas that are undercover, secure and easy to access.

P Easy to access disabled car parking

From 26 November disabled car parking will be available at:

- The Alfred Centre car park P1 **P₁**
- The multi-level visitor car park P2 (Ground Floor) **P₂**

Car parking will **no longer** be available at Centre Block.

P **\$** Reduced car parking fees

Reduced car parking fees for people with disability permits will continue.

'Pay and Display' parking will be introduced next to Radiation Oncology from 28 November.

P Change supports ED Redevelopment

The redevelopment of our Emergency and Trauma Centre means that the Centre Block car park will become an ambulance zone, providing important hospital access for patient transport.

i For more: see alfredhealth.org.au or call 9076 3244

Part of **AlfredHealth**

As a consequence the Alfred centre multi-level car park has become increasingly full early in the day or there are often lengthy delays waiting to enter. Please consider alternatives to driving in and parking if you are able to.

Street parking in and around the Alfred is either metered or a mix of permit zone and up to 2 hour free in select side streets.

PLEASE clearly display your current disabled parking permit on the car dash board right side up at all times.

Alternatives you will be familiar with :

- Tram 72 along Commercial Road in either direction from or to the city with stops outside the Alfred centre or the main block. Trams 3,5,6,16,64,and 67 utilise St Kilda Road in either direction.
- Buses 216,219 and 220 all stop outside the Alfred.
- Prahran Train Station at Greville Street is approximately 2 kms from the Alfred if you are feeling energetic.

For those with a physical disability i.e. using crutches or a walking frame, or are frail/elderly, volunteer drivers can assist with pick up and return from/to home at certain times of the day. Please call the Transit Lounge on 9076 3131 Monday to Friday to discuss the appointment time and day with a minimum of 48 hours' notice required during working days. Unfortunately wheelchairs are unable to be accommodated under this scheme.

If you are running late for any reason please call the HTC on 9076 2179 to inform us as such, rebooking your appointment or need to talk to one of the staff further.

Alex Coombs & Jane Portnoy, Social Workers
Haemophilia Treatment Centre Team
Alfred Health

How to access disabled parking at The Alfred

From 26 November 2016



theAlfred



Important notes

Disabled car parking spaces located at:

- The Alfred Centre Basement car park **P1**
- The multi-storey car park (Ground Floor) **P2**

Concession parking fees remain the same

No parking at Centre Block Ambulance zone only

Ambulance only zone
Non-emergency patient transport

Entrances

For more: see alfredhealth.org.au or call 9076 3244



CONNECTING with our community

HFV Mens Retreat 2017

What a weekend! I've just returned from a superb weekend away at Lochinver home-stead. As always it was set up perfectly for us and our needs. The staff at Lochinver are wonderful and really go above and beyond to make us feel welcome, relaxed and well fed. Sharon was at her best in running our meditation session and we all had the opportunity to enjoy a massage.

There were wonderful conversations around haemophilia, our experiences, challenges and accomplishments. There were lots of discussions not only around our health but our families, work and other interests and above all a lot of laughter!

It was so good to see a new face at the retreat this year and of course all the guys from previous years. We made some great connections and all really benefited from participating in the retreat.

Thanks to all those who attended the weekend. Personally I gain so much from it and come home feeling totally pampered – such a positive and successful weekend. I hope you can join us next year!

Zev Fishman



Do you live in the ANGLESEA region?

Please join us for lunch at our
annual Family Community Camp

You are invited to join the HFV team, many HFV families and people in YOUR area with haemophilia and other bleeding disorders for lunch and a chat! Lunch is provided by HFV - so bring your kids, bring your parents.

12pm Sun 30th April

CAMP WILKIN

ANGLESEA

Please RSVP by Fri 14th April on
9555 7595 or email to info@hfv.org.au
BOOKINGS ARE ESSENTIAL

ALL INVITED!

Help to support Haemophilia Foundation Victoria programs & services

Pre-order your NEW 2017 | 2018 Entertainment™ Membership now!

20% of every membership sold contributes to our fundraising. Help us achieve our goal by sharing this link with your Friends and Family. Thanks for your support!

www.entertainmentbook.com.au/order-books/1834x75 or click on the link on our website.



GRANDPARENTS & FRIENDS LUNCH



You are invited to join Marie, Jackie and other grandparents and special friends of HFV families for lunch at the Brandon Hotel.

This is a wonderful opportunity for extended care givers within our families to meet each other and share the challenges faced by themselves and their loved ones. The benefits of connecting with other families and hearing about achievements and successes and sometimes hurdles that have been overcome can be immense.

WHEN: 12pm Sunday 19th March 2017
WHERE: Brandon Hotel, Carlton North

Bookings are ESSENTIAL 9555 7595
 Please advise of any dietary requirements

**CONNECT
SUPPORT
EMPOWER**

Haemophilia Foundation Victoria
Presents

The Haemophilia Red Charity Ball



Friday 20th October 2017
 7.00pm – 12am

Maia, Shed 14, Central Pier 161
 Harbour Esplanade, Docklands

Dress code – Formal with a touch of red

The HFV Fundraising Committee invite you, your family, friends and colleagues to consider attending The Haemophilia Red Ball which will be held on Friday 20th October 2017.

This event is designed to raise much needed funds that will directly support valuable HFV member programs and to raise awareness of haemophilia and other related bleeding disorders. This will be a fantastic opportunity to promote awareness of the difficulties faced by our members, build stronger relationships with our community's funders and to raise funds to support our member community.

We have been fortunate enough to secure a high end venue at Maia, Shed 14, Central Pier 161, Harbour Esplanade, Docklands. The evening will include dinner, drinks and entertainment. A silent auction will be held on the night and we hope to have an extensive range of high end auction items available. The event will be targeted mainly at corporate sponsors in order to maximise funds raised. We would, however, hope to see a good number of our community represented at this event. It will be a wonderful way to celebrate Haemophilia Awareness Week 2017 in style. The ticket cost has not been finalised as yet however it is likely that the cost may prohibit some of our members from attending. If you are unable to attend there are still several ways in which members can support this fund raising event:

- volunteer to assist in the planning of the event
- volunteer to assist at the event
- assist in selling tickets to the event
- speak to your local businesses and contacts about items which could be donated to sell at the silent auction
- investigate any opportunities to sell corporate tables to the event

Further details on how to purchase tickets will be available in early 2017. If you have any inquiries about this event please contact the HFV office on 9555 7595.

Thank you for your support!

diary dates

MARCH

19 Grandparents and Friends Lunch

APRIL

17 World Haemophilia Day

28-30 Family Camp

30 Regional Visit to Anglesea

JUNE/JULY

TBA Regional Visit to Warragul

TBA Ladies Day out

OCT

12-14 Haemophilia Conference
Melbourne

20 Haemophilia Red Charity Ball

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

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

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



**18TH AUSTRALIAN & NEW ZEALAND CONFERENCE
ON HAEMOPHILIA & RARE BLEEDING DISORDERS**
Melbourne • 12-14 October 2017

SAVE THE DATE

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:

- 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.

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

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
7375

Website: www.hfv.org.au

Fax: (03) 9555

Email: 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 2017 eleven members attended the retreat, including a number of first timers, 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

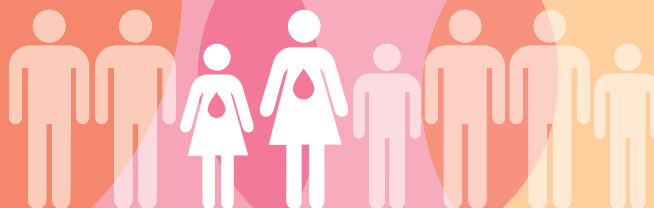
Our Boys Toys Day Out is a wonderful opportunity for our boys to get together with other boys with haemophilia or related bleeding disorders and to spend the day with their dad or another significant male in their lives...grandfathers, uncles or family friend.

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

WORLD HEMOPHILIA DAY 2017 | APRIL 17

HEAR THEIR VOICES

On World Hemophilia Day let's come together to show our support for the millions of women and girls affected by bleeding disorders.



facebook.com/wfhemophilia



[@wfhemophilia](https://twitter.com/wfhemophilia)

Follow the latest World Hemophilia
Day development at #WHD2017



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA