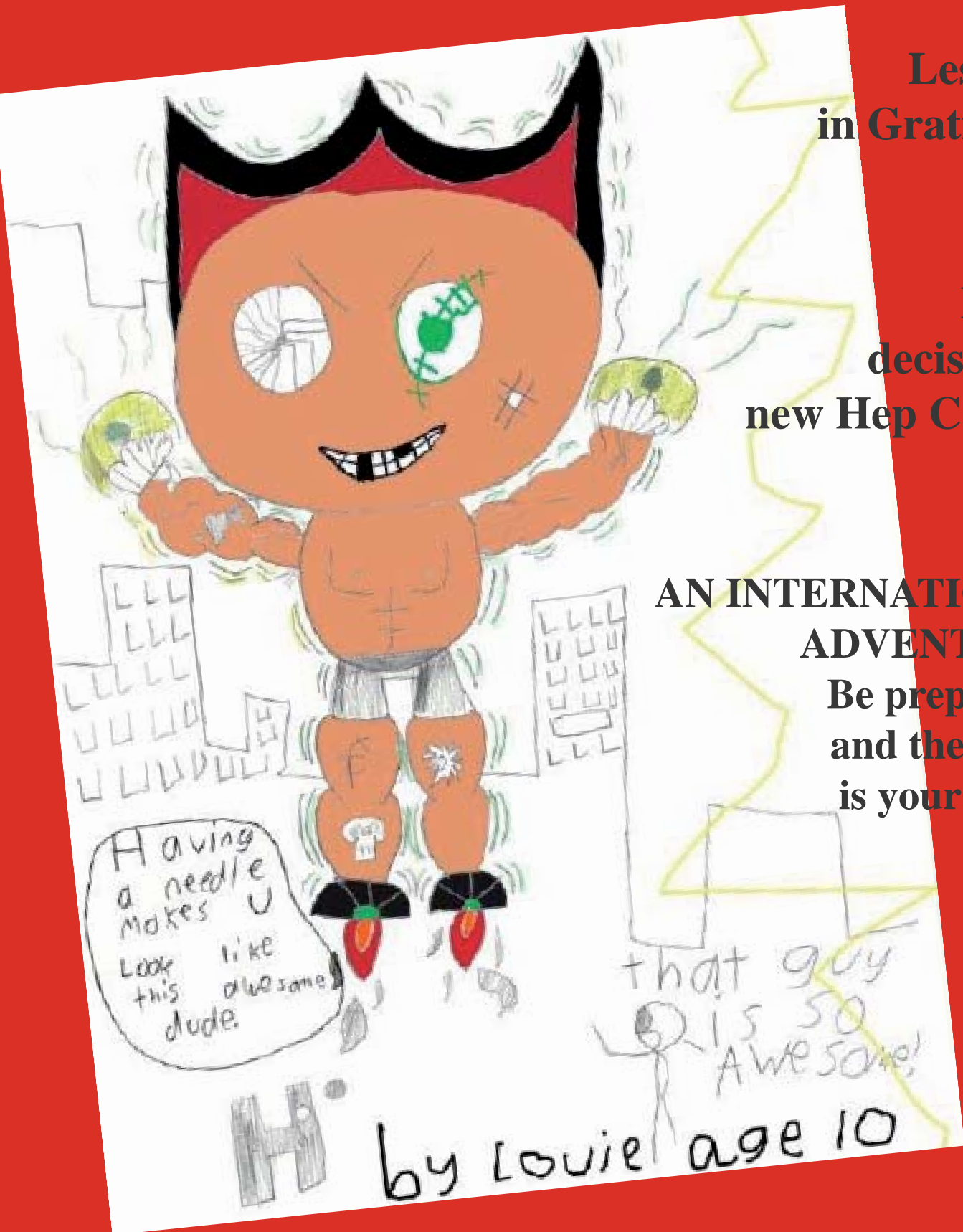


THE MISSING FACTOR

**Lessons
in Gratitude**

**PBAC
decision on
new Hep C drugs**

**AN INTERNATIONAL
ADVENTURE:
Be prepared...
and the world
is your oyster**



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Haemophilia Foundation Victoria Inc

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DIARY DATES

Grandparents & Friends' Lunch — 2nd Aug

Peer Training — 29-30th Aug

Ballarat Regional Visit — 30th Aug

17th Australian & NZ Conference — 1 to 3 Oct

Haemophilia Awareness Week — 11 to 17 Oct

2015 Ladies Day Out — 18th Oct

2015 Blood Brothers Camp — 20 to 22 Nov

Committee of Management

President

Leonie Demos

Vice President

Sharron Inglis

Treasurer

Zev Fishman

Executive Member

Ann Roberts

General Committee

Jodie Caris

Karen Donaldson

Carol Ebert

Donna Field

Another couple of busy months at HFV by the Committee and staff.

Family camp was an enormous success. Such a special time for families to come together and share great food, a lot of fun and a few stories...sometimes happy, sometimes sad. Thanks to the Department of Health for their ongoing support in subsidising this camp. All the camps are very important events on our calendar. For those that haven't joined us yet I encourage you to discuss with our staff and see if you can come next time.

In my short time as President I have had a few important meetings with our valued stakeholders. With Julia and Andrea I have visited both HTC's and been able to hear about the many issues facing our families in their healthcare. I have met with Sharon Caris from HFA several times and was very privileged to attend the National Council and meet other presidents and representatives from associations in other states.

HFV continues to be strong but in all the conversations I understand even more deeply the need for our community to stay focused on our goals and to support each other with the many challenges some of our community face. Sadly in recent times the associations in South Australia and Tasmania are no longer able to be a viable organisation and Victoria needs to continuously pull together to stay strong and exist into the future. Meetings with our funders are scheduled in the near future and with the hopeful continued support from government HFV will continue to grow from strength to strength.

The Committee of management has decided to reduce the meetings to bimonthly in the hope that this will free up some time for our overloaded staff to concentrate on projects and the demands of their work. Committee is moving towards creating more specific sub committee structure to ensure that

A word from *our* president, Leonie Demos

we are focused on the priorities we have identified in the strategic plan and to attract members from our community to join us to share their specific skills. If you would like to join any of these projects please contact the office and any of us would love to have a chat.

There are changes to come as we prepare for future years. However as your Committee is it critical that we have your input in to what you would like these changes to be. Committee is looking at both the Living Well and the Bursary Support application and criteria's that are applied. Far too many of our members are doing things 'tough' at times and the committee takes the responsibility of offering any financial support very seriously. However, with so little money available we need to do so with consideration of many factors and with equality to make sure there will be opportunity for everyone to apply if they need it. The committee is your representative and we want to hear from you as to what you consider to be the priorities as to who to support. Please contact the office and I am very sure Julia and Andrea would be very happy to have a discrete and confidential conversation with you. Your view is very important and we truly look forward to hearing from you.

Lots of exciting things on our horizon. National conference in October at the Gold Coast, Peer support training in Creswick later in the year, Youth camp for the Blood Brothers and many more things so enjoy another interesting newsletter and particularly our bursary submissions from members that feature heavily in this edition!

Enjoy the beautiful autumn leaves as we prepare for winter. Stay safe, stay well and most importantly stay in touch with HFV – we need you.

Leonie

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

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

WOW – What a location and what a team!

I'm delighted to report that we had another hugely successful Family Camp at the beautiful Forest Edge CYC.

As the name suggests we were at the edge of a forest, sitting amongst rolling hills with a river running through. Such a peaceful location and wonderful opportunity for us all to recharge our batteries.

The camp kicked off on the Friday night with a BBQ, cooked by our youth leaders and some dads. We got to settle into our rooms and whilst the kids watched a movie, we managed to put our feet up and enjoy catching up with old friends and meeting a few new HFV faces.



On Saturday morning, we kicked off early with some stretches led by the lovely Karen Donaldson (HFV member and physiotherapist). Janine Furmedge very kindly joined us and brought with her some training equipment for accessing veins. She spent time with the kids and parents, talking through the correct techniques. Some of the older



2015 HFV FAMILY CAMP

boys happily demonstrated how they do their own treatment – offering tips to the younger boys. It is easy to forget what a daunting and confronting experience it must be for parents performing treatments especially early on. This designated treatment time session is a really important aspect to our camp. It is not only educational, empowering and motivating it is of course necessary and quite moving! To watch the older boys take the time to support the younger boys at this session really does highlight what our community is all about.



And then it was time for the activities led by The Purple Soup team! There were low ropes, high ropes (yes I was terrified), archery, river sledging, indoor rock climbing and of course our mums and dads secret business!

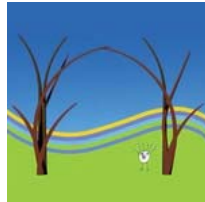
It really was a fun packed day that was polished off with a good old fashioned trivia night run by James, Lynn, Chloe and Nick Roberts. The perfect way to end a great day.



Our Sunday morning followed a similar format with the opportunity for kids to try out some different activities. I was invited to attend the adults mentoring session. This was a very powerful ses-

sion that was run by Bec from Purple Soup - such a strong, motivational and empathetic leader. The aim of the session was to help participants understand that sometimes you do need to rely on others for support and that you don't have to travel this path alone. It was a particularly powerful session with time for reflection in the forest and a HFV web - symbolising how we can continue to work together as a community to help support one another.

Another particularly nice aspect to this camp was the connection to the local community in Neerim South. Donna Field, one of our wonderful committee members, lives in the area and arranged for a member from the Neerim District Progress Association, Phil Henshall, to come and speak to us about the group and the significance of the Bower Bird to the area. Bower Birds are attracted to blue, hence our blue theme!



A big thank you to all involved in making this camp a huge success, including the camp sub committee, Andrea McColl, the Purple Soup Team, the CYC team, Ken Kercheval (Neerim District Financial Services), Phil Henshall (Neerim District Progress Association Inc), Karen Johnson (Neerim District Community Bank) members from the Neerim Community, Tip Top Bakeries Dandenong for providing the bread, Janine Furnedge for spending her hard earned day off with our community and sharing her knowledge and expertise, our youth leaders for being so community spirited and minded and finally to the Victorian Department of Health for seeing the value in Peer Support by financially supporting a grant submission from HFV!

Julia Broadbent



If you haven't been to a HFV family camp before and you are thinking about joining us in 2016, here are some comments from families that attended which hopefully might persuade you...

- *Excellent! The secret whisper was really good as were the high ropes etc*
- *Loved the adult activity with Purple Soup, very touching.*
- *Good mentoring program*
- *Blindfold activity with Bec was amazing. Empowering and provided a means of connecting with new families*
- *The parent activities were really amazing. It's so important for me to know I have such a great support network of people to talk to and share with.*
- *Blindfold and reflection time was wonderful. Beautiful location*
- *Loved Bec's session. She is such a brilliant leader. We need her at each camp!!!*
- *Loved the camp, enjoyed the friendships and the relationships, friendships we made and catch up on. Enjoyed the activities, all of them! Outpost restaurant had great atmosphere.*
- *Purple Soup great, love it when we did big groups activities – life's busy and to spend more time with kids in a fun, relaxed environment is great!*
- *Good to find out how funding works and realise how valuable this is to us.*
- *Youth leaders were amazing. They enabled parents to be able to enjoy and participate in the activities without having to worry. Thank you all.*
- *Purple Soup handled things professionally and tactfully*
- *Another fantastic camp! Thank you to everyone who had a hand in planning. They are a very special part of our life and we look forward to them each year!!*
- *Amazing to do high and low ropes. Ladies time out great time together, sit and chat*
- *Trivia night awesome – thanks to the Roberts. High ropes awesome.*
- *Great activities and support. Found there were items good for both adults and children.*
- *The fashion parade was fun. Trivia was funny and good interactions with other families. The environment was great. Archery was new good thing to try. Rock climbing was good challenge for the kids*
- *Kept busy without feeling under pressure, made you stop and think and appreciate what you have and what you CAN achieve*
- *Loved the trivia*
- *Trivia and High ropes were fantastic*
- *Good pace, enjoyable activities fun to join and watch. Trivia night wonderful, a lot of fun*
- *Awesome program. Thank you to everyone involved.*

BLOOD BROTHERS CAMP 2015

- **ARE YOU AGED 12-25?**
- **ARE YOU A GUY WITH A BLEEDING DISORDER?**

COME AND JOIN OTHER YOUTH FOR AN AWESOME WEEKEND AWAY AT OUR 4TH BLOOD BROTHERS CAMP.

All accommodation and food is provided and transport is available from the HFV office.

Registration forms will be sent out with the August magazine.

Not been before? You or your parents are welcome to speak to our office staff or our HFV Youth Leaders before you book. Please call 9555 7595.

PORTSEA

**20TH-22ND
NOVEMBER 2015**

HAEMOPHILIA – Lessons in Gratitude

My name is Kate and I am a single mother of two astounding young men, Sana, 12, and Made, 10. Haemophilia became part of our family's story when Made was diagnosed at 7 months old. It has been a bitter sweet tale since then, full of moments that have elicited tears and laughter.

We were living in Bali when Made was diagnosed and I made a heart wrenching decision to relocated back to Melbourne just before his first birthday. We left all our belongings and assets, our hopes and dreams for our future life, the boys' paternal family and their cultural ties. We literally arrived in Melbourne with a box of clothes and some of the boys' toys, and we have been building our lives back from scratch since.

Treatment in Bali was expensive, ineffective and Made was not expected to live beyond his fifth birthday, if at all. Life in Australia has been a blessing because we rarely remember Made has haemophilia except for factor days. I cried with sheer joy when I learned Made would be able to live a 'normal' life. There are days when Made tests us all with his moods, boundary pushing and really loud voice, but he is alive!

It took a long time for me to be able to relax into having a haemophiliac son. Not only did haemophilia carve a rift between me and the boys' father and family, but I felt it robbed me of everything bar my boys. I put my life on hold to deal with Made's treatments and, what seemed like endless hospital and doctor visits. I didn't realise I grew resentful under my veneer of calm acceptance.

In honour of the expense to our community for keeping my impish child alive and healthy, I endeavoured to do volunteer work for many years. It helped keep me actively involved in the workplace and gave me a sense of contributing to something outside of myself. Those years volunteering for the CFA and a local Special Development School made me appreciate how necessary it is to see how others live and that I am not the only one challenged by life.

In some ways, haemophilia took away from me, yet has given back two fold. I would never have imagined that we'd achieve all we have as a family, and individually. It was my dearest wish that Made and Sana experience life to its fullest. While financially things have been tough, I made sure the boys got as many opportunities as I could manage to know that life is a precious gift. There have been times, which many of you will relate to, of late night rushes to hospital with a child in pain and copious amounts of coffee to keep awake on the drive home at daybreak.

I could wax lyrical about all the glorious achievements we have amassed, but they all point to one fact: severe haemophilia is something I would never wish on my enemy, but it has taught me the humble gifts we get simply by being alive. I am grateful to have two sons who can laugh, wrestle, climb trees, devise plots to overtake the world, sing loudly with me in the car and do anything they please. While I allowed haemophilia to halt me in my tracks initially, I am now living a life more authentic and grounded. I am a better parent, better employee, better citizen and better to myself than I would be sans haemophilia.

At 41, I have just commenced an apprenticeship as a heavy vehicle diesel mechanic with a family owned company. Haemophilia has given me ample reason to prove that life can go on in the face of change, adversity, sadness and loss... AND excel prior expectations! I thank haemophilia for the ample gifts it has granted us.



Here is Kate challenging herself on the High Ropes at the HFV Family Camp!

AN INTERNATIONAL ADVENTURE:

Be prepared...and the world is your oyster

In January of this year I travelled to the USA for 10 days of travel around the states of California, Arizona, Utah and Nevada. This trip was my first international adventure and as such I had to learn many important skills even before I left Australia including how to get a passport, organize notes to allow my treatment factor across international borders and finding travel insurance that would cover haemophilia related incidents. The trip itself started peacefully with the help of my faithful travel companion, Purple Soup Director Tim

Marchinton who was full of helpful hints and tips on how to not get robbed, lost or scammed. So without a hitch my treatment kits passed easily through customs before a 15 hour long plane flight across the Pacific Ocean to Los Angeles involving Castaway, Pompeii and a lot of patchy sleep. With a conveniently planned 12 hour stopover in LA Tim and I had some time to check out some local tourist attractions and took the time to take a bike ride along Venice beach to check out the beautiful Santa Monica Pier, and after some classic Americana eating went to the California Science Center to see the Endeavour space shuttle.

Our next flight to Phoenix, Arizona arrived at 2am in the morning where we checked into our hotel and crashed after way too many hours of being awake. The next few days after that Tim and I spent at the NACCHO conference (North American Camping Conference of Hemophilia Organizations) representing Purple Soup and Haemophilia Foundations Australia and Victoria both learning great ideas to bring home to Australian camps and sharing our ideas with haemophilia organisations from around the world. As a part of the conference Tim and I submitted a short video on the journey of one of our campers and a written presentation on Purple Soup's 'Learn to DJ' camp theme as a program that has an element that can be brought home with campers; both of which were chosen in the top candidates and we were given a second chance to present them to the entire conference which was a great honour. Through the conference I got to meet some truly amazing people from Turkey, Canada, the Netherlands and of course the US who all ran camps for kids with Haemophilia. These few days were an amazing learning experience and it was truly inspiring to be around some of these brilliant people and learn how and why they do what they do; Tim left with a great determination to bring Purple Soup camps to Turkey and Nigeria and I have



Be the best camper session at NACCHO

great hopes of one day getting to visit one of their camps myself. The conference ended with a dinner and party at a Mexican Cantina where it was announced that while our video hadn't made it past the top three our 'Learn to DJ' theme had won us second prize in the NACCHO Cup!

After the conference was over the final part of my adventuring plan involved travelling through southern Utah with Tim and our friend Matt through some absolutely stunning national parks. We were however temporarily sidetracked by the opportunity to go to the Pro Bowl; a game of American Football played the week before the Superbowl itself. Matt quickly and unquestionably recruited me as a Patriots supporter and we went to watch the game. It was so much bigger, brighter and louder than any sporting game I'd ever seen in Australia.



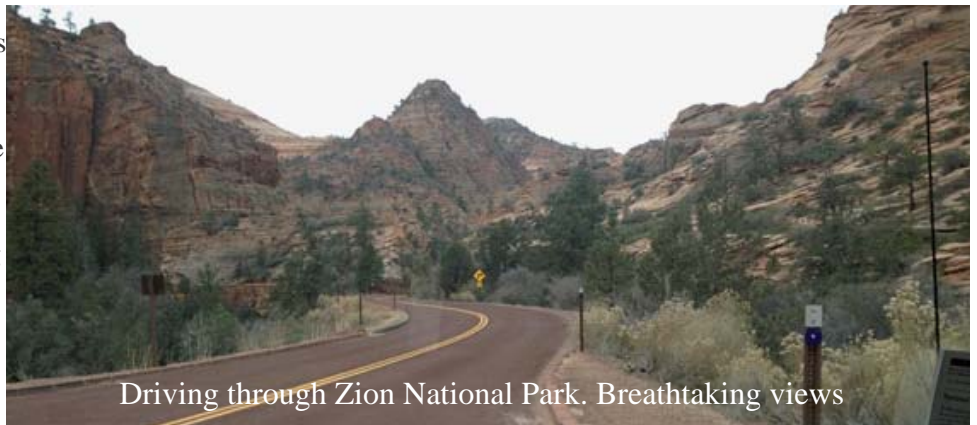
Antelope canyon. Absolutely beautiful

The next few days the three of us drove around in an RV (complete with fridge to stop my factor warming or freezing) travelling through some of the most beautiful scenery I've ever seen including the Grand Canyon National Park, Antelope Canyon and Zion National Park. This would have had to be my favourite part of my trip; with my camera over one shoulder and my little esky of emergency factor over the other: hiking through these great American national parks through landscapes I had seen countless times on a screen but had never been able to truly experience until now. I would need pages upon pages to do all the landscapes justice so I won't go into great detail here but what I will say is that no movie or picture I have ever seen has truly captures to enormousness and majesty of the grand canyon; standing on its edge in the dead of night it was as if the world truly was flat and that I was at its edge.

My last night in the US was a late one, walking down the Las Vegas strip and looking into some of the famous casinos (though being just under 21 years of age the option of gambling was totally unavailable), the lights of which could be seem filling the horizon from over 2 miles away.



Second place in the NACCHO Cup!



Driving through Zion National Park. Breathtaking views

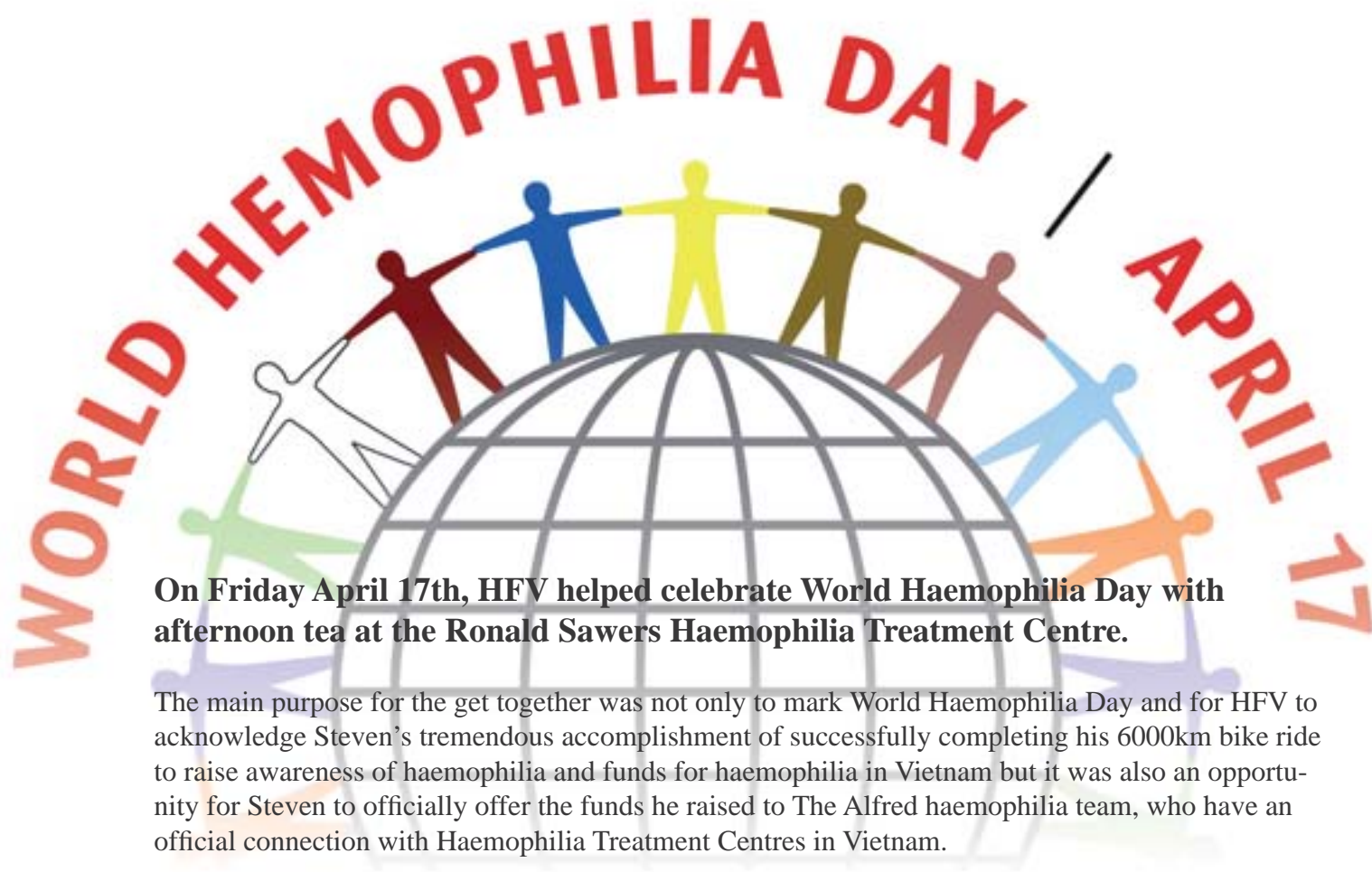
After flying out of Vegas back into LA most of my final 12 hours before my flight back home was spent at the Universal Studios theme park, the highlight of this being the famous Universal Studios tram tour where we went through sets of a lot of famous movies and tv shows including Desperate Housewives, Psycho and War of the Worlds.

Totally exhausted after far too many hours of being awake I fell asleep during the takeoff from my flight to wake 11 hours later only 4 hours away from home. The end of my adventure was really quite easy; I had no trouble getting through customs and my family was there waiting for me to take me home where I was more than keen to get some more sleep and spend the next few days fighting the jet lag.

For those of you out there with haemophilia thinking that maybe you want to travel the world I would definitely recommend it; I have well and truly caught the travel bug and can't wait for my next chance to go out and see the world. The prospect may be scary for now but if you prepare well and travel with friends you trust then I can almost guarantee you will not regret it.



Closing of the conference. So many new friends!



On Friday April 17th, HFV helped celebrate World Haemophilia Day with afternoon tea at the Ronald Sawers Haemophilia Treatment Centre.

The main purpose for the get together was not only to mark World Haemophilia Day and for HFV to acknowledge Steven's tremendous accomplishment of successfully completing his 6000km bike ride to raise awareness of haemophilia and funds for haemophilia in Vietnam but it was also an opportunity for Steven to officially offer the funds he raised to The Alfred haemophilia team, who have an official connection with Haemophilia Treatment Centres in Vietnam.

Dr Huyen Tran graciously accepted the funds given to the Haemophilia Treatment Centre for use in the

Vietnam twinning project. Dr Huyen's initial thoughts are that the funds may go towards a new training project at a centre later in the year. The training will have a hugely positive impact on people affected by haemophilia in the region as has the crutches that were purchased with funds raised by HFV members.

HFV will continue to hold the funds until the treatment centre team travels to Vietnam later in the year.

What a huge achievement for Steven and such a great way to acknowledge his success on World Hemophilia Day.



Epic ride raises awareness, cash for haemophilia



MELISSA TOWNSEND DANDENONG
LEADER APRIL 16, 2015 12:00AM

STEVEN Taylor will never forget the elation of seeing the Sydney Opera House on the horizon after weeks of cycling across the country.

The 34-year-old haemophiliac recently completed an epic cycling adventure across Australia to raise awareness about the bleeding disorder.

In September, he began the journey from Brisbane to Sydney, where he took the train to Perth, then cycled back to Melbourne, ending his 6000km journey in February in Dandenong, where his family is based.

Mr Taylor raised more than \$4,500 to support other people with haemophilia, particularly those in third world countries where modern treatments are not readily available.

“We’re fairly well looked after in Australia, but overseas it’s a different story and there are no treatment options available for a lot of people,” he said.

“I took my time with the journey, and it was very difficult with a lot of physical work and very isolated.

“It was also a really good thing for my health — I got into shape and lost a bit of weight.”

On Friday, to coincide with World Haemophilia Day, Mr Taylor presented his donations to The Alfred hospital.

The money will go towards ongoing support for the Haemophilia Centre’s Vietnam Twinning Project, whereby staff from The Alfred share their expertise on the disorder with a “twin” city, Hanoi.

Reprinted with permission from The Dandenong Leader

HFV PEER SUPPORT TRAINING SESSION

Expression of interest

29th-30th August 2015
Novotel, Creswick

HFV is running a Peer Support Training weekend in August. The aim of the weekend is to up skill current and potential peer support leaders and also train regional members to create a peer support network across Victoria.

Accommodation and meals will be provided.

Sat 29th - Training session, 10-4

Sun 30th - Fun Group Activities 9-12
Lunch 12-2

Please contact the HFV office on 9555 7595 or email julia@hfv.org.au if you are interested in participating.

Further information will be sent to potential attendees.

2015 REGIONAL VISIT TO BALLARAT

Sunday 30th August, 12-2.30
Novotel Creswick

If you live in the Ballarat Regional please come and join our HFV staff, committee and other HFV members for a casual lunch.

The lunch will be held at the Novotel in Creswick and will follow our HFV Peer Training Sessions so there should be a good number of people in attendance!

Bookings are essential through the HFV office on 9555 7595 or julia@hfv.org.au by 7th August.

WOMENS WISDOM

A word I'd not heard of

Haemophilia, a word I had not heard of, until my mum sat me down one day;

She explained I was a "carrier" and had some things to say.

Honestly it was a bit scary, upsetting believe me;

But mum said it was genetic and showed me our family tree.

My mum is also a carrier, her dad a bleeder too;

And we traced haemophilia ancestry all the way back to 1802!

I have a medi-alert necklace, which I wear and no-one sees;

For me it's peace of mind and my parents are at ease.

Medication and understanding gets better with each passing year;

And the lovely Dr Chris Barnes, helps settle my silly fears.

I can be cheeky and to look at me you would not know;

I have a bleeding disorder because it does not show.

For not only am I carrier, but I am a bleeder I can tell;

A simply tooth extraction, cost me a night in hospital having factor replacement as well.

Friends find it hard, to completely understand;

As it isn't like having asthma or eczema on your hand!

I am in Grade 6, I love school, sport and my family heaps;

I just happen to have haemophilia, but it no longer gives me the creeps.

I plan on getting married and one day a family of my own;

But for now I am just happy living with Mum and Dad in my happy home.

Us girls need to stick together, there are more of us out there;

It no longer needs to be scary, when we have stories like mine to share.

We are a little different, to the boys and what they suffer;

But who knows; us girls...we might be even tougher!

By Sian, aged 11

LADIES DAY OUT 2015

This year we are participating in a fun group dance session, where we will first watch a beautiful Bollywood dancer and then learn a short routine ourselves.

Sunday 18th October 2015

**Studio Doors will open at 10.45
11am start 1 hour class.**

**Dance Baladi Studio
at The Aegean
(above Aegean Restaurant)
19 Brunswick St, Fitzroy, 3065**

It is suitable for all ages and abilities. Dance can be a fun way to de-stress and unwind and may be something you have not considered as a relaxation option.

We will all take part in the **entire day** as a group. The activity part of the day is an important element in what makes this group work and a lot of effort goes in to making sure it's suitable for all!

**Numbers are limited -
bookings essential through
the HFV office 9555 7595.**

YOUTH YAK

What an inspiration!

Here are our HFV Youth Leaders. They all took on active roles at our family camp ranging from running sessions for the younger children, BBQ duties and child minding during the evening movie sessions. We were also very lucky to have Isabelle on board who was our exceptional camp photographer!

It really was a pleasure to watch these young people in action. They clearly understood their mentoring and peer support roles and were great role models for the younger kids.

They spent time with the younger kids during the treatment sessions, reassuring, advising and supporting them.



So a big thank you to our future HFV leaders Scott, Ben W, Chris, Tim, Matt, Isabelle, Emma and Ben I from the HFV staff and committee!

Youth Leadership Training Day

In January of this year a group of six of HFV's young best and brightest led by Tim Demos and Ben Inglis took the time out of their weekend to better themselves as youth leaders of Victoria's haemophilia community.

Here is what Ben said about it...

'The day was spent learning and discussing what it means to be a leader as well as what sort of leaders we wanted to be and what were the best things we had ever seen happen at HFV events and how we were going to make those things happen.'

'The day delved deeper into how we deal with confronting situations and into more light hearted learning of quick and easy games to run. Overall the day was a great success with all involved excited for the upcoming family camp where they could test their new found skills as leaders'.

A big thanks to all those involved, particularly Ben Inglis and Tim Demos for organising and leading the day.

If you would like to be involved in future HFV Youth events please contact julia@hfv.org.au

HEP C UPDATE

PBAC DECISION ON NEW HEP C DRUGS

HFA welcomes the PBAC recommendation for the following hepatitis C treatments to be added to the Pharmaceutical Benefits Scheme (PBS) for the treatment of chronic hepatitis C:

- Daclatasvir (Daklinza®) in combination with Sofosbuvir (Sovaldi®)
- Ledipasvir with sofosbuvir (Harvoni®)
- Sofosbuvir (Sovaldi®)

Describing its decision, the PBAC stated that “new treatments for HCV were very effective” and would offer options for treating people with genotypes 1 to 6.

The PBAC also recommended that the new all oral treatments should be listed in the General Schedule, rather than the Section 100 Highly Specialised Drug Program. This would mean that prescribing these treatments would no longer be limited to specialist clinics.

However, clearly the PBAC was not satisfied with the proposed treatment prices and advised that the Australian Health Minister should negotiate lower prices for them to be cost-effective.

NEXT STEPS

"Government funding is needed urgently, for these medicines to be listed on the PBS so they are affordable to Australians with hepatitis C," says Gavin Finkelstein, HFA President.

The next step in the process is for the Australian government to consider the PBAC recommendations and make decisions about funding. We hope the cost of these drugs can be negotiated successfully with the pharmaceutical companies without delay. Access to these medicines is critical.

“GAME CHANGERS”

These new treatments have been described as “game changers”. They are part of the new wave of Direct Acting Antiviral (DAA) drugs that are far more effective against hepatitis C than the previous treatments. Most of these treatments are already available in other countries.

In clinical trials they have had very high success rates – over 90% for some – with few side-effects, and shorter treatment courses. Some need to be taken in combination with other medications (eg, interferon, ribavirin, ledipasvir) to be effective. Some will be available in interferon or ribavirin-free combinations. Some have had encouraging results even with people who previously had unsuccessful treatment or who have advanced liver disease.

AND IF YOU HAVE HEP C?

In the meantime - if you have hepatitis C and a bleeding disorder, remember that you would need to have your liver health assessed before you could be considered for treatment:

- Make sure you have your liver health checked regularly
- If you don't know where to start, talk to your Haemophilia Centre about a referral
- Stay in touch with your hepatitis clinic about what's new
- Don't forget to go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable at the moment
- And for comprehensive care, let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

2014...*Living and Learning*

As I sit and reflect on 2014, the year that was, I am surprised and yet relieved. I wonder in my mind how it was possible to climb out of the hole on those deeply dark days, rise to the challenge of being a mum on my own and playing with the thought of how in the world could life possibly ever be the same.

The kids and I moved in January, it was difficult, sad, even tragic. The kids seemed to cope OK. We started getting into a routine, school went back and things were beginning to be slightly normal. What's normal? I ask myself that question every day to this day.

Josh was doing well in school, he was studying VCE law in year 10 and going great guns, he was working part time and all round he was performing amazingly considering what he had to endure on a daily basis. He, as a typical teenager decided that doing his twice weekly factor was a pain. He started suffering with more bleeds, longer lasting more painful bleeds. My heart broke. I tried to tell him to keep up with his factor, but unfortunately he had to learn the hard way. He wanted to start weight lifting, that was fine but I stated to him that he must start gently but once again he lifted too heavy and severely bled into his abdomen. Two weeks in hospital, my heart broke once again.

In that time I was diagnosed with stage 2 breast cancer, surgery removed a 6mm tumour, I was back having more surgery when the cancer spread. I was terrified. I was angry. Why me? What did I do to deserve this?

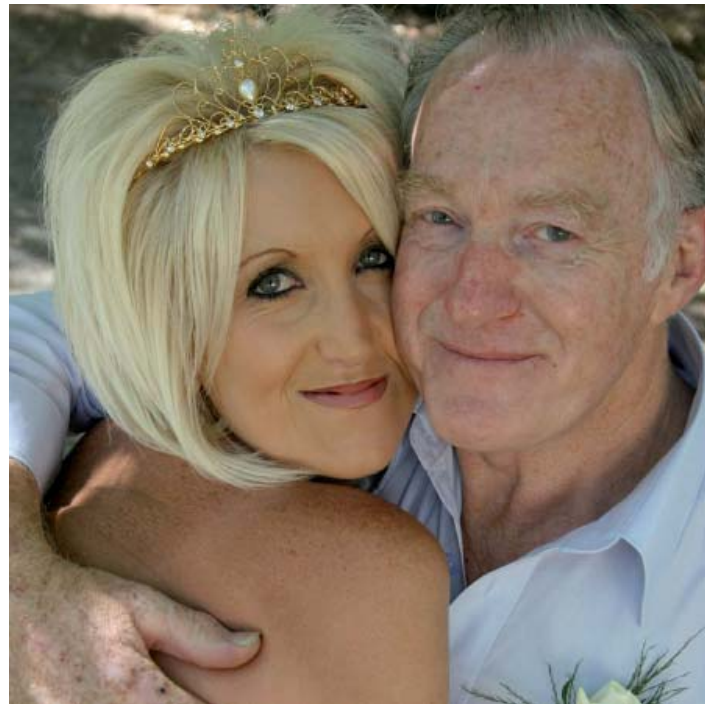
My dad turned 70 in November, he has haemophilia, as a young girl I watched him be taken away by many ambulances, sat by his bed for multiple hours and watched in horror at the pain he has endured. During it all, he has never complained, but in fact fought it every step of the way, what a bloody amazing human. He worked all his life, provided for his family and just never, ever gave up. I am so proud of my dad's strength and determination. Nothing gets in his way.

Which brings me back to me. I am the carrier of haemophilia, I knew there was a risk before I had my children but I didn't care I wanted them anyway, if my dad could live through it so could any one of my children, And they did.

Through the year there have been so many lows, but through them I looked at my dad. I thought to myself,

bloody hell, if he can do something then so can I. And I did. I enrolled myself into college to do a diploma of Counselling, I found myself a part time job and I bloody got on with it. I have done this while raising four kids on my own, battling cancer and just day to day daily events. My dad has continued to support my every decision, pick me up when I nearly fell and encouraged and pull me through. I plan on graduating in July, I plan on entering university and making a better life for myself and my children. I know I can do this because I have my number one fan cheering me on at the sidelines.

My dad.



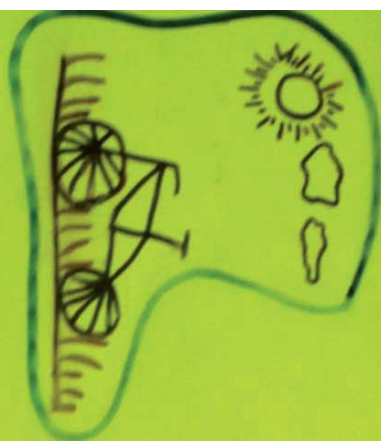
Haemophilia...don't let it consume your life, take it and own it and let it make you into a stronger and brighter individual. You are the captain of your ship, you can achieve anything you want if you want it bad enough.

Try it...I dare you.

Sharyn.

My life with haemophilia

by William Donaldson



I love riding to school with Mum,
Archie, Dad & our dog Xena.



I know I am lucky... I have
haemophilia AND I can
have factor.



My biggest passion is surfing 'cause I
love it so much I can now do cartwheels &
once caught a barrel in NZ.

I like basketball because it's sports
And I like trying new things.

By Will,
aged 7

Join your Haemophilia Treatment Centre Team for a fun filled
BOYS DAY OUT at the...

MELBOURNE AQUARIUM

When: 9.30am on Wednesday 1st July 2015

Where: Melbourne Aquarium

Who: YOU and kids like you, your mum/dad/or significant adult
AND US...Janine and Julia

Cost: FREE! And food for the kids will be provided.

The visit will include the new art aquarium ~ where you'll get to do some colouring in of different animals, scan them in and watch them swim around in the virtual tank! There will be an education staff member to take us on a special tour around the aquarium, so we can learn some special facts about our weird and wonderful animals. Hope to see you there!

RSVP by 15th June to Julia Ekert either via email ha.htc@rch.org.au or phone 9345 5099

Supported by Haemophilia Foundation Victoria Inc

FOR KIDS RANGING FROM 4 YEAR OLD KINDER TO AGE 11 YEARS

GRANDPARENTS & FRIENDS' LUNCH

12.30 - 2.30

SUN 2nd AUGUST

Latte Lounge

502 Canterbury Rd, Forrest Hill, VIC, 3131

This venue is very accessible from the freeway, easy parking and great reviews!!!

If you haven't attended this event before feel free to call the HFV office and chat to the staff.

This event started out as a group of grandparent who got together once a year to chat about the highs and lows of managing their grandchild's bleeding disorder and to build that important network of extended support.

This group has since grown to include friends of the family as there are often significant friends, aunts or uncles that play a key role in supporting a child with a bleeding disorder and/or their family.

Please come and join us and meet other supportive people from our community.

Bookings essential through the HFV office on 9555-7595 or andrea@hfv.org.au

2015 HFV MEN'S RETREAT

We held our 2015 Men's Retreat during March at the beautiful Lochinver Farm Homestead in Carisbrook.

There were 10 guys who came along for a great relaxing weekend and got to participate in massage sessions, meditation and pain management sessions designed to help the guys manage their condition.

A big thanks to Zev for organising this event and encouraging other men from our community to join in and benefits of this weekend.

Here is a comment from one of the guys that attended, "To all the boys, it was great to meet you and hear a little of your stories. I think it is through times together like this weekend that provides great opportunity to learn and grow from each others journey. Thank you for that opportunity."

HFV are hoping to run another retreat in 2016 so we hope to see some new faces join us then!



The 17th Australian & New Zealand Conference on Haemophilia and Related Bleeding Disorders will be held at the QT Hotel, Gold Coast 1-3 October 2015. The theme for the conference is “Facing the Future Together”.

After the very successful WFH World Congress in Melbourne last year we look forward to a stimulating and exciting Australian & New Zealand Conference where we will discuss and debate issues and follow up on ideas and connections made.



Our conference will bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn more about care and treatment in Australia and New Zealand, and around the world, and to plan for the future.

The program has topics and issues to interest everyone including the following and more:

- Living well with bleeding disorders
- Best practice treatment and care and how this is measured and monitored
- Supply and safety of treatment products, including long acting clotting factors
- Family planning
- Youth matters
- Helping children live with a bleeding disorder
- Improving your joints
- Women's health and bleeding issues
- Understanding von Willebrand disorder
- Managing pain
- Hepatitis C treatment and care – including new treatments
- Living well with HIV
- The global bleeding disorders picture

Limited subsidies are available to assist with conference attendance for HFV members. Please see the enclosed conference form.

The program will include people living with bleeding disorders as experts as well as health professionals and others presenting from different perspectives.

Who should attend?

- people with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners – all ages
- health professionals – doctors, nurses, physiotherapists, social workers/counsellors and other health care providers
- treatment product producers, suppliers and service providers
- policy makers and government officials
- haemophilia Foundation volunteers and staff

We look forward to seeing you on the Gold Coast!

Gavin Finkelstein, President, Haemophilia Foundation Australia
Deon York, President, Haemophilia Foundation of New Zealand
Dr Scott McRae, Chair, Conference Program Committee

The Department of Health and Human Services fund the Australian Drug Foundation (ADF) for a range of drug prevention work.

They have developed a new resource, 'Preventing alcohol and drug problems in your community' that looks at a community approach to prevention. There are also many other resources such as interactive online resources on the effects of alcohol and what a standard drink actually is. These resources are available for viewing at adf.org.au

1 in 5
women
drink alcohol
while pregnant

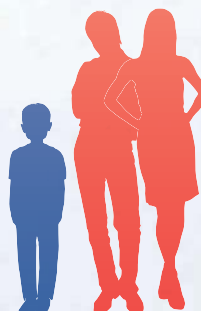


Drinking during pregnancy can cause miscarriage, premature birth and stillbirth. It can also cause learning and memory difficulties, behavioural problems, poor growth, organ damage and facial abnormalities in the child. The Australian Alcohol Guidelines recommend not drinking during pregnancy.



By the age of **12**
a child will have seen
1300+
alcohol ads on TV.

Parents are
the most likely
source of
alcohol
for 12-17
year olds.



8 out of 10



Australians
over 14 drink alcohol.

**DRINK
DAILY**

Australians
aged over 70
years are the
most likely
group to drink
daily.



7% of Australians
misuse pharmaceuticals
(e.g. painkillers, tranquillisers)
at some point in their life, about
the same amount that will use
meth/amphetamine.



1 in 10 workers
say they have experienced the
negative effects
of a co-worker's misuse
of alcohol.



1 in 5

Australians over 14
drink at levels that put them
at risk of alcohol-related
harm over their lifetime.

Alcohol and other drugs **cost**
Australian workplaces
\$6 billion per year in lost
productivity.



AGE

10, **20, 30, 40**
50, 60, 70, 80, 90

Illicit drug use is most
common among people
aged 20-40 years.



\$7b
is generated
by alcohol
related
tax.
But

alcohol costs society
\$15.3b annually
and illicit drugs
\$8.2b annually.



Alcohol caused
more than **twice as**
many deaths (3,494)
than road accidents
(1,600) in 2005.



Go to
DrugInfo.adf.org.au
for more information and
references.
You can also download this
page as a pdf.

The most **common**
drugs people seek
treatment for are:

alcohol (46%)
cannabis (22%)
amphetamines (11%)
heroin (9%).



IMPORTANT

**Talking about
AOD harms**

There is no doubt that alcohol and other drugs, when misused, can cause a large amount of harm. However, when talking about these harms it's important not to exaggerate them and to acknowledge why people would drink alcohol and use drugs, such as for the pleasurable effects, to ensure you come across as a credible source of information on the topic²⁸. To find accurate information on the effects of alcohol and different drugs visit DrugInfo.adf.org.au

MyABDR update

From the HFA and National Blood Authority MyABDR Team



WHAT'S NEW?

The latest release of MyABDR in January 2015 brought you more improvements and features:

- Faster synchronisation
- Bug fixes to help users better manage their inventory levels and copy forward routine prophylaxis treatments

"Since the last update I have found MyABDR easier to use – with better inventory control and speed to load and update treatments. I think every update has been creating a better – and great - tool for people to use. In my family it has become a key part of our haemophilia treatment and management."

David, MyABDR User, Tasmania

You may also have noticed the new ABDR/MyABDR Privacy Consent form that you will probably have completed by now.

NEED HELP?

Don't forget your friendly MyABDR Support Team are available 24 hours a day, 7 days a week to help you with any problems.

Finding it hard to make the time to ring? The team is available at any time, even outside business hours, or send them an email and they will ring you back at a time that suits you.

T: 13 000 BLOOD (13 000 25663) E: myabdr@blood.gov.au

For more information on MyABDR, visit www.haemophilia.org.au/myabdr.



Your friendly MyABDR Support Team, from left to right: Vaughan, Petra, Andrew, Rebecca, Jo, Lachlan, Lyndsay and Nathan.

our community



BROUGHT TO YOU BY THE
**FLIGHT
CENTRE**
TRAVEL GROUP™

quickbeds

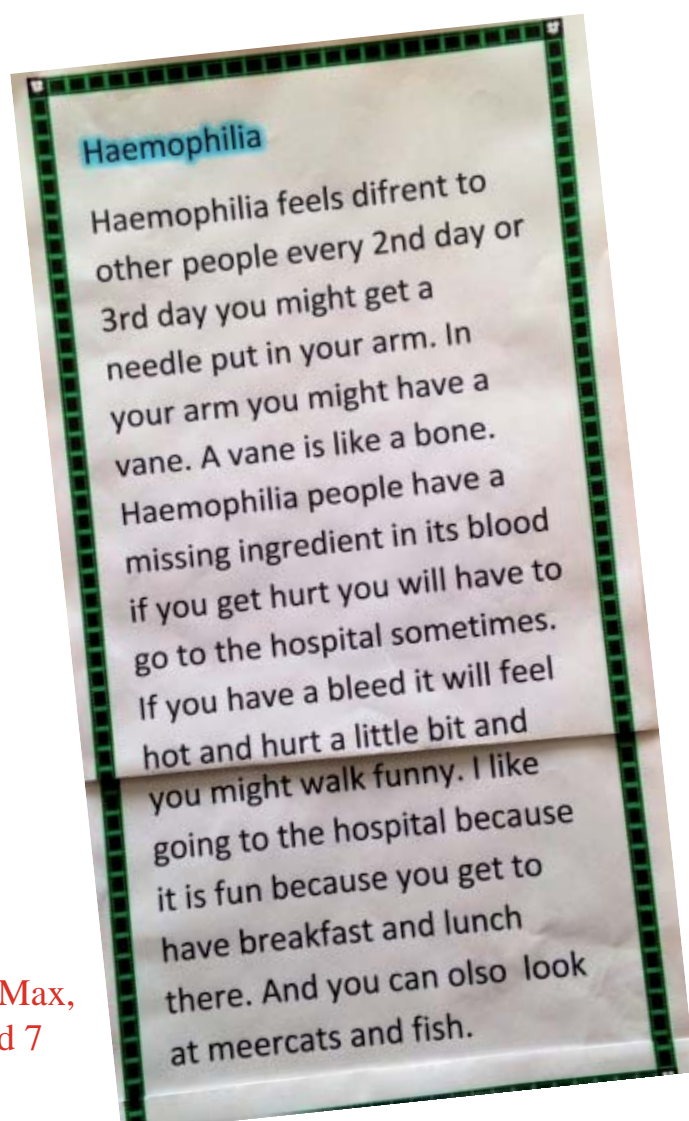
Grassroots Fundraising Program

Supporting local sport & community groups

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

IT'S VERY SIMPLE!

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



By Max,
aged 7

We hope you enjoyed all the bursary submissions that have been featured in this edition.

We always get very good feedback regarding member articles as they usually have the greatest impact on our other members.

We are always delighted to receive member stories and articles so please if you have a free moment and think your journey and experiences may help others, put pen to paper and share them with us.

Your efforts would be greatly appreciated and articles can be emailed to julia@hfv.org.au

HAEMOPHILIA CENTRES

HENRY EKERT

HAEMOPHILIA TREATMENT CENTRE

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

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Julia Ekert | Office Data & Product Manager
Melinda Cumming | Social Worker

RONALD SAWERS HAEMOPHILIA CENTRE

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

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

2015/16 HFV MEMBERSHIP RENEWALS

Membership renewals will
be mailed out in May

Payment is due by the 30th June 2015

Please note there will be slight changes
to the membership structure

HFV MEMBER SERVICES

Membership Fees:

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

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

Ambulance Subscription Subsidy:

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

To obtain an Ambulance Subsidy:

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

Other Subsidies:

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

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

Care and Counselling:

This is available through your treatment centre.

Magazine:

Your quarterly magazine offers information and details of upcoming events.

Website - www.hfv.org.au

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

The HFV Office:

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

We are located at:

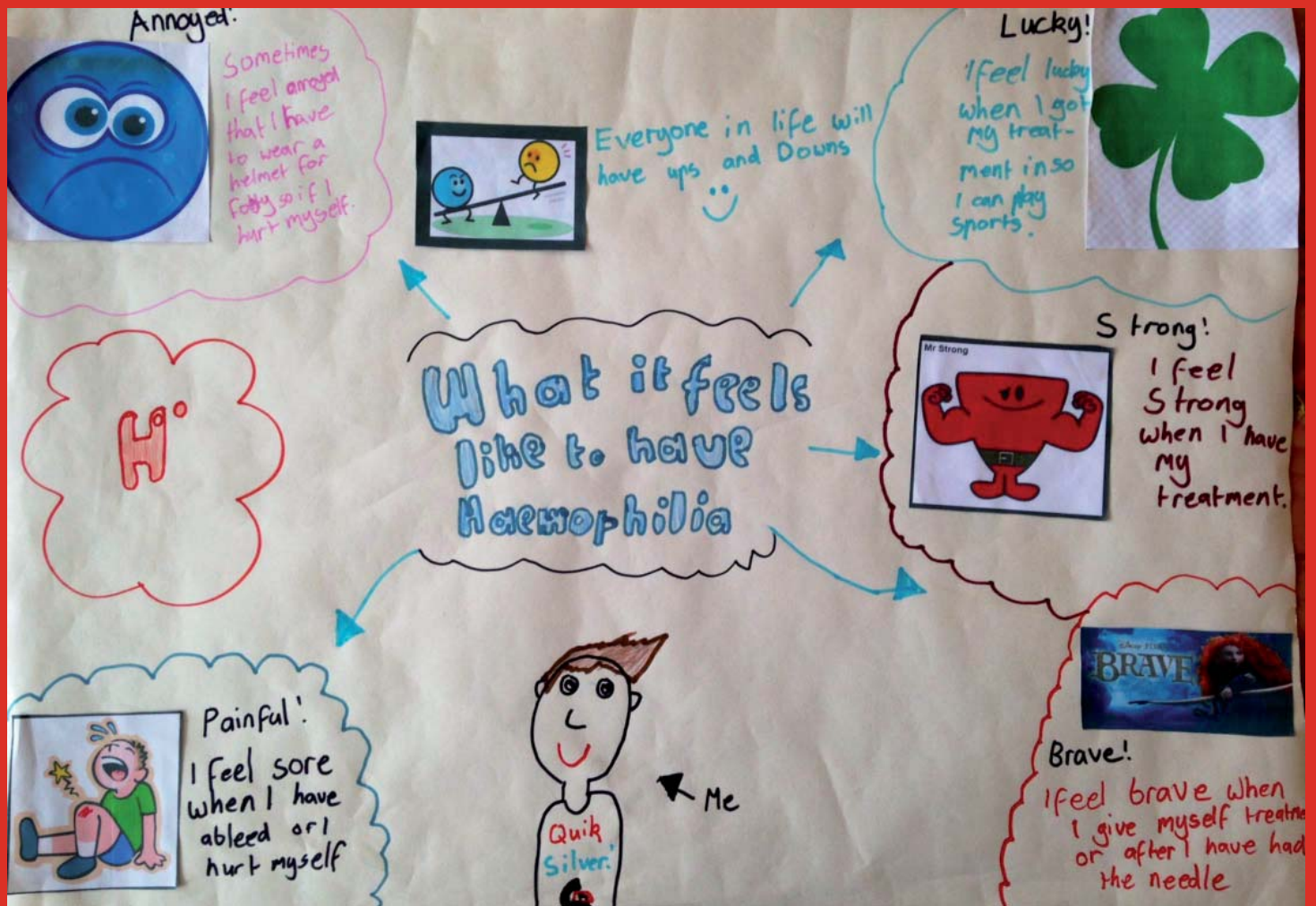
13 Keith Street,
Hampton East, Victoria, 3188.

Phone:	(03) 9555 7595
Fax:	(03) 9555 7375
Website:	www.hfv.org.au
Email:	info@hfv.org.au

Steven Taylor (aka Randall Stephens) arrives home after a mammoth bike ride across Australia raising awareness of haemophilia and money to help assist people with haemophilia and other related bleeding disorders in Vietnam.

On World Haemophilia Day, Steven and his mother Liz joined with our HFV staff, Julia & Andrea, Zev Fishman (HFV treasurer) and Hannah from HFA to present the funds raised to Dr Huyen Tran and Penny McCarthy from the Alfred Haemophilia Team.

The funds will be used to support specific projects in Vietnam through the twinning program to assist with much needed training. This will have a huge impact on the health outcomes for the bleeding disorders community in Vietnam.



by Nathan, aged 10