

THE MISSING FACTOR

A journey through
the generations

ELIMINATING the
burden of stigma

Growing up with
Haemophilia

connect • support • empower



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18th Australian & NZ Conference on
Haemophilia & Rare Bleeding
Disorders

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HFV is committed to Child Safety.

Our Child Safety Statement is available for review on our
website www.hfv.org.au

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Editor: Julia Broadbent



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PRESIDENT'S REPORT

CONNECT SUPPORT EMPOWER

SUPPORTING OUR FAMILIES WITH INHIBITORS

Finally we say goodbye to winter and welcome our spring bulbs and hopefully some much missed spring warmth.

The National Conference is coming soon and I hope you are all able to attend. The program sounds amazing with lots to learn on treatment products and care across the country. Some of our staff and members are presenting alongside their foundations and it is a very important time to bring our knowledge up to speed and to meet with others that share our challenges. The conference dinner is also always worth attending as well as the women's and men's breakfast. As the host state we are all looking forward to welcoming our interstate friends and health providers to continually challenge ourselves for best practice in health care and peer support in partnership.

Following on from a busy week at the conference we get to dress up and dance the night away at the first Haemophilia Red Charity Ball. Thank you to everyone that has so generously supported the event already by donations, purchasing tickets and many other ways. The subcommittee have been absolutely amazing in all their efforts and we are all getting very excited as the time approaches. It will be a very fun event indeed and a must 'be there' on your social calendar. If you missed out this year for tickets the good news is that we may be able to do it again in the next year or two with your support...provided our wonderful subcommittee don't disappear. They have demonstrated to all of us what is possible with generosity of time and brain power! Time to start dress shopping...

As a committee we are well aware that there are a number of families that are currently managing inhibitors. I was very fortunate that my son Tim didn't develop inhibitors. We watched other families struggle through the burden of inhibitors and could see the toll it took on all members of the family. But it is only really those that have been through those challenges or are still in the midst of it that understand. With that in mind, we are hoping to engage some families who have been impacted by inhibitors so that we can offer peer support to those families currently managing inhibitors and in the future. It may be that families can share their story with us, or maybe willing to speak to other families managing inhibitors. For the families I have spoken to the onset of inhibitors came as an unexpected shock and challenge so it is important we are able offer these families some extra support. If your family has experienced the impact of inhibitors please give Andrea or Julia a call and we can look at the best ways to support these families.

The committee is currently planning the AGM and Christmas picnic in November. A fabulous event in a very significant location....you will need to read the newsletter carefully to find out the details. It is a chance to meet the wonderful committee that work so tirelessly behind the scenes as well as a chance to thank both Andrea and Julia at HFV for their amazing work as always. If you are considering stepping up to join the committee I am always available to have a chat as are any of my colleagues. Many hands make light work and you all have something to offer so please

consider joining us - the nomination forms are enclosed!

As always ongoing funding needs to be our priority looking forward to next year and beyond. We always welcome anyone with ideas on increasing resources or have skills in writing funding applications or similar supports to offer. We are only a phone call away.

As I sit snuggled up listening to rain and wind I am hopeful that the next time we meet it will be warm and lots of daffodils in bloom. Enjoy your welcome to spring and hope to see you at one if not all of the very exciting events in our shared calendars

Yours in partnership,

Leonie Demos

TAKE CONTROL

POWER over your future medical care and treatment



The right documentation can give you some power over your future medical care and treatment.

As some of you may recall the 10th March 2011 was a day my life and world changed for me. Until that date I had been living my life fairly carefree, travelling and working as a social worker at the Alfred Hospital Infectious Diseases Team and Ronald Sawer Haemophilia Treatment Centre for 3 years. I had relocated from Perth, where I had lived all my life to start in a new social work clinical area and enjoy the many great lifestyle options Melbourne had to offer.

You never know what is waiting ahead and changes that can occur in an instant. I still remain unable to explain why I went from planning to head off to work one morning as I stood on my 3rd floor balcony to now being reliant upon a electric wheelchair and personal carers every morning 7 days a week 6 years later.

Like many people I hadn't given much thought about the "what if's".

I had a unit I planned to hold onto, dutifully done my will that made provisions for my estate and any remaining extended family in Perth. Being single and away on the other side from my family, who would be responsible to make medical or financial/lifestyle decisions on my behalf if I wasn't in a position to do so one day? Even if I was partnered too it is not as clear-cut as you or even best friends know.

I recently attended a workshop on Advanced Care Planning, which is a way to ensure your thoughts and wishes about your medical care and treatment can be recorded and known by your GP, treating team and hospital. I add that the guidance and in-put of the medical team is still highly sought and not to be ignored. As we age our body keeps changing no matter how healthy we think we are or attempt to be. For those with existing medical conditions this can add more complexity and risk.

I am not trying to sound alarmist but to bring to your attention that there are a few ways that we all can ensure that our wishes for

medical intervention can be communicated to your medical team, treating hospital or if you find yourself in another hospital not familiar with your medical history.

Who should know your wishes regarding your health and medical decision making if you can't communicate them yourself? Well lets start with your significant other(s). Whether you are married, de-facto or being single it can become essential someone has recollection of what you want regarding treatment or level of intervention to either restore your health or keep you comfortable and pain free. Same Sex married relationships aren't legally recognised in Australia yet, therefore I would recommend people consult a lawyer, arrange Enduring Power of Attorney and potentially an Advanced Care Plan to capture your wishes to their fullest degree and avoid the potential for conflicts to arise between family and significant others.

Whilst all relationships will be respected generally in the health care system, the powers to make

decisions about medical treatment follow a pre-ordained list of “persons responsible” that follows the legally recognised relationships and blood family connections.

The timing of having these conversations with your chosen confidante, in my opinion would be best when you are at your healthiest and competent. You may have recently had an event that began to make you think “what if”. We can all make assumptions about who takes over, even I did as a social worker after almost 20 years in health.

Usually when we are admitted to hospital, we, or someone on our behalf might fill in a registration form with the words: “next of kin” “Emergency contact” “Person Responsible” requiring name and contact details. Whilst helpful, do they know what we want to happen to us from the medical treatment point of view? What if our personal, religious, spiritual or cultural beliefs influence our thinking, would the person whom the treating team talk to know how important that is to us?

There is a hierarchy of decision makers that the medical team can turn to based on the level of connection to you as the patient. If in the event you have no one that fits the criteria, your next option is to appoint someone you trust, or a publicly appointed person can be applied for, as your Medical Enduring Power of Attorney. The appointed person will have the powers to make decisions on your behalf when you are unable to do so due to an accident or illness. This is one area that can give power to those who are in a same sex attracted relationship, those without close family ties living or due to family dysfunction.

Before you go ahead and document your wishes and sign it off, PLEASE inform the appointed person that you intend to do so. They don't need another sudden surprise during a traumatic hospital situation to be told they have a

significant level of responsibility on your behalf.

Role of

- Next Of Kin – the closest living relative such as wife, husband, domestic partner, sibling with whom your medical team will discuss your medical situation with but are they the person deemed to be “Person Responsible” - see below.
- Emergency contact – similar to the above but a person who can be nominated to be the go between you, your medical team and the outside world of family and friends
- Guardian – legally appointed person to make decisions if you have no one else capable or willing to do so
- Person Responsible – is the 1st person in the list below who is available, willing and able to decide:-
- Person appointed under the Enduring Power of Attorney (medical treatment)
- Person appointed by VCAT (Victorian Civil and Administration Tribunal – check with your respective states as to the equivalent) to make the decision
- Person appointed by VCAT under a Guardianship Order
- Person appointed under Enduring Power of Attorney with power to act
- Person appointed in writing by the patient
- Spouse or domestic partner
- Primary carer (not paid carer)
- Nearest relative aged 18 and over, which means the eldest:
 - Child
 - Father or mother
 - Brother or sister
 - Grandfather or Grandmother
 - Grandson or Granddaughter
 - Uncle or Aunt
 - Nephew or Niece

MEPOA – Medical Enduring Power of Attorney is a person given authority by you to make only medical decisions beyond your own capacity is diminished. There are other Enduring Power of Attorney for Financial and Lifestyle to manage your affairs. If you have any of these forms completed, please ensure your GP, hospital, medical

team, case manager, social worker, family and significant friends are aware of their existence. A copy should be noted as a true and sighted copy to be held in your medical records. If you attend other hospitals ensure they similarly have a copy of each

- Advanced Care Plan records your wishes in regard to the types and level of medical intervention you wish to be carried out in emergency and life threatening events. Each hospital has their own version of these but if you have documented one, I would recommend that you can arrange for another copy to be held by the other hospital as well should you be admitted.

The MEPOA and Advanced Care Plan can work together to ensure that your nominee in the MEPOA is guided by your documented wishes and consider the advantage of these documents being on file in your medical records.

By writing this, I hope it will give rise to more careful documentation of our client's wishes and decision-making. These documents enable us to have conversations with our clients to ensure their health beliefs are recognised and followed by those often left to make hard decisions at difficult times.

This has been written from a Victorian perspective, so please check with your respective state authorities how this applies.

Alex Coombs
Social Worker
Ronald Sawyer Haemophilia
Treatment Centre

Growing up with haemophilia... you gotta be willing to take the hits

Tim Demos (HFV Member) was recently invited to speak at an education seminar at the Royal Children's Hospital for teenagers with health conditions in their last few years of high school.

Tim is a HFV member, was a patient at the Royal Children's Hospital and also worked at the RCH as a Youth Mentor in the Adolescent Transition Department.

Tim has kindly shared his experiences of growing up with haemophilia and his positive outlook on life.



My name is Tim and I was very honoured when asked to come here tonight and get the chance to talk to all of you because at the end of the day everyone in this room is one of my peers. All of you here tonight in some way, shape or form, had or will continue to have your struggles with a health condition. I was diagnosed at a very young age with severe haemophilia which is a genetic bleeding disorder with no cure. It causes internal bleeding into muscles and joints, often even without any form of injury. To try and prevent bleeding I self administer IV clotting factor at home twice a week, I encourage everyone here tonight to come up to me after this talk and look at my track marks from my needles..... bet you thought you'd never hear that from a presenter.

Growing up with haemophilia had its challenges, understanding why I was different from other kids and had to do needles was difficult. Frequent trips to the hospital to manage bleeding episodes were never a welcomed thing. But I didn't come here tonight to give you a sad story about my condition, in fact I hope to do the opposite.

Now some of you may think what I say next is absolute rubbish but I really do consider myself lucky to have a health condition. Yes, there are times when you feel like you're stuck in a hole that you'll never get out of when your body or your mind lets you down and to be honest I'm sure there are more of those times to come, but the strength, compassion and resilience I have developed through facing these chal-

lenges are my greatest advantage. I am a strong believer that those who grow up with health problems are forced to grow up a little faster than others, how many of your friends can claim they might have had a surgery at a young age, or had the mental strength to endure a long stint in hospital, how many could stay positive in the face of monthly hospital appointments and numerous medication all before they've finished high school?

You all in one way or another have faced challenges that in a perfect world you shouldn't have had to confront. But looking at you all here tonight I can see that you've all come out the other side better for it.

Now I understand that all these things I'm saying may sound wrong

to a lot of you, and to be fair I'm wrong about a lot of things, I thought pokemon GO would never get old or repetitive, I thought for years that Sherlock Holmes was a real person and I only just realised last week that the symbol for the chain store target was an actual target, who'd have known? But this.... this is something I know I'm on the money about. You may not be able to see it because I know when I was your age I definitely couldn't but your personality and characteristics that you've shaped over a lifetime of experiences and challenges outside of what most people consider 'normal' is your biggest strength. Your potential to do well in VCE, VCAL, sport, music or whatever you aspire to do is only limited by how much you all choose to apply yourself. Just harness that grit, stubbornness and motivation you have towards managing your health to your personal pursuits and I promise you, you'll be capable of great things.

I am a paramedic with Ambulance Victoria which is a job I consider myself lucky to have. Paramedics was always something I wanted to do, I know a lot of you are probably getting asked on a weekly basis about what you want to do after secondary school. And for some of you like me you may know the answer, some of you think you know the answer and change your mind 3 times and some of you will just flat out have no idea. Don't put too much stress or pressure on yourself to figure out your life's plan in the next few years. That would be like me asking you to order something from a restaurant before you get there and see the menu. I know everybody loves a chicken parmigiana but how do you know that the chicken parma at this particular restaurant is any good? It takes time and an open mind.

All you need is a starting area or a general direction that can show you what's out there. The only reason I bring up my job is because it's taught me a lot about opportunity. I work in Dandenong which can be a pretty rough area. There's a lot of good people trying their best and unfortunately there are those that cause trouble and throw away the chances that life gives them. Chances to improve their lives and make a positive difference.

Although very infrequent, I have seen some things that will always stay with me, things that are confronting and things that no words can describe. I often attend people who have no choice in their future whether it be through accidents, unforeseeable events or even circumstances far more tragic. If you take away one thing from today please let it be this; don't squander the opportunities that lie in front of you. Yes, all of us have been dealt the short straw at times, but to be sitting in this room here today, with all of the speakers, resources and family here to support you is a golden opportunity. You have the abilities and characteristics to achieve

whatever it is that you want to, so take that chance. Apply yourself and commit. You won't always succeed and failure is a scary thing, it's something that I know all too well. But you can't reach the finish line if you don't take the first step. You'll never get to delicious cookie half of a maxibon if you don't eat the gross chocolate half first and you'll never look great in those skinny jeans unless you're willing to wear them in.

I'd like to finish off with one of my favourite quotes of all time from a great fictional scholar named Rocky Balboa, you may have heard of him. He said "it's not about how hard you hit; it's about how hard you can get hit, and keep moving forward. It's how much you can take, and keep moving forward. That's how winning is done. If you know what you're worth, then go out and get what you're worth. But you gotta be willing to take the hits".

Tim Demos

A journey through the generations

My name is Kim and I lived with haemophilia for forty-seven years. I have been married to Karin for thirty eight years, we have two beautiful daughters Melissa and Jessica and four adorable grandchildren Zaine, Harry, Luca and Grace.

As I approach my sixtieth birthday I have been asked by HFV to reflect on my life's journey with and without haemophilia. What life has been like for me and my family. What life is like now. What life is and will be like for my grandson - Harry who is ten and was born with haemophilia.

I am a baby boomer, born in 1957 when there was very little if anything known about haemophilia and its treatment. It was not until my younger brother (Shane, born 1959) had bleeding problems post birth that our parents were recommended by our local doctor to take us both to the Alfred Hospital to see Dr Sawers. We were both then diagnosed with haemophilia A severe <1%.

Living in coastal southwest Victoria meant trips to the Alfred only for major bleeds throughout my life, which I know has been the case for many. I can vividly remember my first admission as a pre-schooler to the children's ward on the corner of Commercial and Punt Roads for a baby tooth bleed that just would not stop.

The thing I remember mostly about that first admission was not the bleed or the treatment, it was the daily screaming of a little boy who had been hit by a car whilst on his bike resulting in severe brain injury. People would come twice a day to move his limbs resulting in him screaming and crying. It was this daily traumatic event that gave me a perspective to the hand I had been dealt in life.

I am not saying life was always great growing up. Sitting on the side of my bed with an ankle in a bucket of iced water for days trying to stop the bleed, simply because there was no treatment available. Going to primary school in calipers to reduce bleeds in my ankles until around grade five. Having to use crutches to get around. Being that different kid with the limp. Because of ankle bleeds I missed a lot of school and struggled to read and count as a result. However growing up in a small family operated mixed business, working in the shop with mum and dad, provided me

with the opportunity to develop a high level in communication skills and the pathway to read and count.

Secondary school was much the same, with frequent bleeds and prolonged periods of time away. However I was able to obtain my Higher School Certificate with the assistance of great teachers and friends. I was also elected Senior Sports House Captain in my final year. Elected clearly not for my sporting achievements or abilities but for my communication and organisational skills.

Following secondary school I applied for and was accepted into Geelong teachers college (Primary). However the college withdrew their offer following their medical review, which everyone had to undergo, because of haemophilia. I have reflected on this many times over the years as the best thing (professionally) that has happened to me, because I took this as an opportunity to review my working future.

The door that opened professionally was working in sporting retail for five years, during which time I married Karin, followed by sixteen wonderful years working and managing recreation and sporting facilities in local government.

During this time our daughters Melissa and Jessica were born.

In the late seventies through use of Cryoprecipitate I acquired non A non B hepatitis, later redefined as Hep C. Then in the mid eighties through Factor 8 acquired HIV. Haemophilia then took a very big back seat at this time as we found ourselves being told I had possibly six months to one year to live.

Clearly life for us all at this time was like a roller coaster, however I was continually being told by my wife I was going nowhere as we had two daughters to raise, at this time aged three and nine months. Karin's positive outlook kept us both going. Sadly we lost my younger brother Shane to HIV in the early nineties, which as it turns out was the start of HIV treatments in Australia. So being in the right place at the right time meant I was able to access medication for HIV. Medication that I am still on, under the supervision and guidance of the unbelievable ID team at the Alfred.



However this thing called Hep C, which was almost forgotten reared its head in the early two thousands and my liver function tests started to go off. Three years later we were told that Hep C was going to kill me unless I received a liver transplant. Again we found ourselves on a roller coaster; haemophilia, HIV, Hep C and needing a liver transplant.

I was fortunate enough to receive a new liver in August 2006 at the Austin Hospital which meant waking up after the transplant without haemophilia, still with HIV, Hep C and a new liver.

Recovery from the liver transplant and living without haemophilia in the first few years post transplant has been like an out of body experience. Living with haemophilia for forty seven years and then not, did take a little adjustment.

Then as my life would have it, treatments to cure Hep C arrived on the global scene three or four years ago. I was fortunate to commence treatment to cure Hep C in mid 2016 and was given the all clear in December 2016. What a Christmas present that was.

So now I live with HIV and the

requirements of my liver transplant, no haemophilia and no Hep C! The thing my life's journey has taught me is the importance of the love and support of family and friends. We have not lost friends due to my HIV status, in fact our friendships have increased because of it and our lives enriched.

The importance to have strong good people around you, who are looking out for you and are honest with you.

To recognise in yourself there are many things we cannot control in our lives due to haemophilia, other medical and life issues, however the one thing we can control is how we respond to them.

We have a choice, we can be negative and give up, or be positive and look at the opportunities ahead.

The developments in the treatment of haemophilia I have seen first hand through my grandson Harry. They are nothing short of amazing. Harry at ten years of age is a great young sportsman who loves his Australian rules football and cricket. Nothing gets in his way due to prophylactic treatment. His future, with potential new and exciting

treatments for haemophilia on the medical horizon, will allow him to achieve his life goals and allow him to live a long and healthy life, a somewhat different life's journey to his grandfather.

Kim Freeman

A DREAM COME TRUE

Chris Bombardier - the first person with haemophilia to reach the summit of Everest

Climbing Mount Everest, the world's tallest mountain standing at 8,848m high, is the ultimate goal for many climbers around the world. By the end of 2016, only 4,469 climbers have accomplished that feat, and at 9:59 a.m. Nepal local time on Monday, May 22, 2017 thirty-one-year-old Denver, Colorado native Chris Bombardier became the first person with haemophilia to reach the summit.

Bombardier has severe haemophilia B, which means his body doesn't produce the protein called factor IX that helps his blood clot. In order to combat the missing protein, Bombardier has to replace the factor through IV infusion treatments. The disorder affects mostly males and only about 400,000 people worldwide — more than 2,700 people in Australia have the disorder.

Despite his disorder, climbing Mt. Everest had always been an aspiration of Bombardier's.

"I'd been dreaming about climbing it for so many years, to actually say that you're going to climb it," Bombardier said. "I don't think it felt real until we were actually standing at base camp looking up at the mountain; looking at the ice fall. It's the most beautiful place I've ever been and the scariest place I've ever been."

Long before his Mt. Everest climb, Bombardier's love of the outdoors started at an early age living at the foot of the mountains in Colorado. Unlike many children with haemophilia, Bombardier's parents didn't confine him inside the house. Instead, he was always active outdoors competing in baseball and taking swimming lessons from a young age. Because haemo-

philia can cause excessive joint damage, his activity levels were made possible through the help of his frequent visits to the local haemophilia treatment center for treatments.

"In Colorado, we're fortunate because the treatment center here is very progressive as far as believing that people can do activities they want to do. A lot of treatment centers, even now, kind of protect people with haemophilia. They try and put them in almost like a little bubble," Bombardier said. "Our treatment center has a very 'Colorado mentality.' We have these outdoor places people need to experience."

Bombardier continued his baseball career all through grade school and went on the play collegiate ball at Doane College in Crete, Nebraska. Once college ended, he wanted to continue his active lifestyle and thanks to his Uncle Dave introducing him to the sport, Bombardier started mountaineering.

Luckily for Bombardier, Colorado has 58 peaks exceeding 14,000 feet in elevation, known locally as 14ers, the most of any state in the United States. Along with his Uncle, Bombardier started in his own backyard, climbing and summing peaks, but had his sights set bigger, climbing the highest mountains on every continent, the Seven Summits. Although only 231 in history have ever completed the Seven Summits, Bombardier was determined, even with a bleeding disorder.

"Ten years ago, it would have been physically impossible for someone with hemophilia to attempt one of our 14ers here in Colorado, let



alone the highest peaks on the seven continents," said Amy Board, executive director of the Colorado Chapter of the National Hemophilia Foundation.

So began his quest for the Seven Summits, Mt. Everest being what he considers the pinnacle of the climbs. But summiting Mt. Everest didn't come easy. While on the mountain he treated more often, doing IV infusions about every 3-4 days because he wanted to be more protected while he climbed. He also had moments of doubt about being able to complete the climb.

"In that little ridge-line near the summit, it's just all rock and ice and like a knife edge. It's a really intimidating looking feature," Bombardier said. "I was exhausted and tired, and I was thinking that this might be too much for me. The Sherpa I was climbing with, named Tashi, came up to me and I told him, 'I think I'm done. I don't know if I can do this. It seems too crazy.' He turned to me and says, 'No, you have a purpose. You're on a mission. You can do this. We can do it together.' Now, you know you have a climbing harness on, and you have tethers with carabiners, which are clipped to all



these fixed ropes. [Tashi] took his carabineer, he clipped it through mine, then he just started walking towards the South Summit.”

Bombardier completed his summit push on Mt. Everest on May 22nd.

“Standing on the top of the world was a surreal experience,” said Bombardier. “Once we reached the top of the Hillary Step, I knew I was going to make it and I started to cry a little. I couldn’t believe I was actually going to make it. When I finally saw the summit I thought about the flag in my pocket and how the guys with hemophilia in Nepal signed it. It made me think about how fortunate I was to be able to have the choice to climb and how this moment will hopefully bring attention to their need and maybe bring better care to people with haemophilia globally.”

Bombardier uses his disorder to advocate for others with bleeding disorders and decided to use his climb to raise money, \$8,484, the height of Everest, to support Nepal’s Haemophilia Society and people are still donating.

In addition to helping the Nepal Haemophilia Society, Bombardier, with the support of his wife, Jess, family and friends, works with numerous organizations including GutMonkey, his local Colorado Chapter of the National Hemophilia Foundation and Save One Life. He also co-founded Backpacks and Bleeders, a Colorado-based organization to get kids with bleeding disorders outdoors and active.



“People with bleeding disorders and other chronic conditions hear a lot of what they can’t do. You should always try to pursue your dreams and passions. I have hemophilia, but my dream was to climb the Seven Summits. Just because you have all these

obstacles and excuses doesn’t mean you should believe them,” Bombardier said. “There’s a quote I really like that says, ‘Whatever your excuse is, it’s time you stop believing it.’”

Bombardier has now completed six of the Seven Summits and has plans to summit the final peak, Mount Vinson in Antarctica at the end of this year. You can find information about all of his climbs and follow his story on his website, Adventures of a Hemophiliac. You can also see the documentary about his epic Everest summit in the forthcoming film, Bombardier Blood.

Article provided by
Chris Bombarier.

Courtesy of the upcoming film,
“Bombardier Blood.”

ELIMINATING the burden of STIGMA

I recently had the pleasure of meeting Anthony face-to-face at a Department of Health Forum. Anthony has recently taken on a role as a Peer Support worker for Straight Arrows. Anthony has been a member of HFV for many years and recently attended the Men's Weekend Away specifically for men with haemophilia and HIV.

I spent some time chatting with Anthony and was inspired by his resilience, kindness, positive attitude and willingness to advocate. Anthony explained that he had only recently disclosed his HIV status beyond family and a select number of friends and had since found a voice in fighting the **burden of stigma**. In May this year, Anthony became a voice for the Positive Speakers Bureau and presented at the Aids Candlelight Memorial on Southbank, Melbourne.

Anthony has kindly shared his speech with us. If you would like to watch Anthony's speech, please go to www.youtube.com/watch?v=B5Y1Xu5xzt8&



It's such a privilege to be here with you on this very special occasion of remembrance.

My story is one of overcoming stigma. In my small way.

I became HIV positive during the early 1980s. Probably before the age of 10.

I have haemophilia, and I was one of many people with bleeding disorders who were reliant upon treatments made from human blood donations. The treatments brought us greatly improved quality of life and relief from painful and damaging internal bleeding. Those life giving treatments also brought HIV. So here I was, a child living with HIV in the 80's, when fear of HIV

was out of control. I heard adults make cruel jokes and derogatory references to people with HIV. Some sectors of society clearly loathed and feared people with the same illness affecting me. For many years, my parents and I did not tell a single other person. It just seemed the safest way to go.

As a child, I began to internalise those negative messages that attacked my sense of value as a person. I could not voice the words HIV / AIDS and I tried not to think about it. I grew up protecting my secret with hyper vigilance. I felt threatened and I feared serious bullying if my secret got out. For a time, haemophilia was closely associated with HIV so I had to find ways to hide my haemophilia

related illnesses. I could not let my guard down, and I had to keep a step ahead of any questions that might come.

Thankfully, I had a safe place to be myself, in the care of my loving parents. I also had the expert support of medical professionals at the Royal Children's Hospital whose care seemed to suggest that I DID have value. Time passed, I didn't fall ill, and life went on. I made the choice to be optimistic and to fight HIV and live the best life I could. As I matured my understanding of HIV stigma increased, and my fears receded to a degree. My ability to rationalise and understand the workings of stigma grew. Even though I maintained the secrecy for a long time, I became

more confident in my ability to control my information.

I decided to disclose for the first time when I was 20. It bothered me that my siblings were distanced from me and the challenges facing me. I did not fear their rejection but I was still extremely nervous. I had to say "I have HIV" out loud. It was really difficult, but it was an important milestone in my acceptance and decision to take control. My siblings embraced me and accepted me.

It took another four years for loneliness to force me to begin disclosing to carefully selected friends. Again, I felt that these people, who felt deeply significant to me, couldn't really know or appreciate me until they understood what I was facing. Those disclosures enabled me to feel more connected to others. It opened up relationships with others who would support and affirm me. Those who would love me.

In recent years, I had the growing nagging feeling that by hiding HIV, I was failing a responsibility I had as a privileged, straight, white, male member of the dominant culture.

So last year I decided to announce publicly that I have HIV - it was something that Jennifer had gently encouraged me to do for years. We both understood the value and the risks.

On facebook I posted a picture of us and our kids, disclosed my status and announced how proud I am to still be here. After years of fearing that others would disclose for me, I chose the circumstances and time and means and made one fell swoop of a disclosure. It felt great to celebrate in that way, and to free Jennifer from the weight of that secret. I was overwhelmed by the supportive and affirming comments that my post received.

I'm able to get up here today thanks to the support and inspiration I've received from others living with HIV. I'm grateful to those courageous men and women, including

my predecessors at the positive speakers bureau, who lived openly and unashamedly, refusing to allow HIV to define them and who spoke up out of love not fear. Equally, I am inspired by many courageous individuals I know personally, for whom public disclosure is not an option. Many of them live silently with HIV, quietly overcoming huge challenges with great dignity, supporting each other and being a family to each other.

Those of you who know me will appreciate just how far out of my comfort zone I am doing this today. And, if we are to end HIV and AIDS together, as our theme today provokes us, I believe we all need to challenge ourselves to talk about HIV more. By telling our stories, as people living with, and affected by HIV, we diminish stigma. By diminishing stigma, we help undermine one of the most significant barriers to ending HIV and AIDS.

When we all return to our routines tomorrow or during the week, I invite you to put HIV stigma busting on your personal agenda. Talk about it more than you normally would. Whether you are positive or not, tell people what you did today. At work, or at home, at church or at the pub, this week, tell them about the stories you heard. Consider sharing something of your story. Take a risk.

Maybe even take the plunge and disclose. Speak with pride and feel no shame. Tell them that hope is high and people with HIV are living full meaningful lives, working, travelling, forming and maintaining fulfilling relationships, having children, and growing old. Speak knowledgeably about Treatment as Prevention, Pre and Post Exposure Prophylaxis, and the implications of undetectability for people with HIV. Encourage your friends and family



ENDING HIV AND AIDS TOGETHER

Join communities around the world in the largest grassroots movement to end the HIV epidemic



Sunday 21 May 2017 · 5pm · Queensbridge Square

members to see to their sexual health checkups if they are sexually active.

Then, remember that you hold your place in this big beautiful HIV family that embraces diversity by definition. Embed yourself in and draw strength from this community. I know I do. When I look out at you all, I am filled with hope, and I feel part of something strong and meaningful. Something that is stronger than stigma.

Anthony McCarthy

WORLD HEPATITIS DAY

World Hepatitis Day is marked internationally on 28 July.

This year we celebrated World Hepatitis Day with the stories of people with haemophilia who have been cured of their hep C.

A NO HEP FUTURE

In 2017 the global community has come together in support of the World Health Organisation's commitment to eliminate viral hepatitis by 2030.

Imagine a future without hepatitis C.

Can we achieve this in the Australian bleeding disorders community?

I AM CURED OF HEP C

The new direct acting antiviral (DAA) hepatitis C treatments are truly revolutionary. In Australia they are available on the PBS (Pharmaceutical Benefits Schedule), which means they only cost as much as any prescription medication. Hepatitis and haemophilia specialists are encouraging everyone with hepatitis

C to come forward for treatment.

- High cure rates - 95% overall
- Few if any side effects
- Tablets – no injections
- Shorter treatment courses – 8-24 weeks.

Eliminating viral hepatitis



We are pleased to hear from Haemophilia Treatment Centres that most people with bleeding disorders have now been treated and cured of their hep C.

What is it like to have the new treatment and be cured?

Paul and Len tell their stories in our new video - Hep C - I am cured! – <https://tinyurl.com/hepc-cure>

WHAT CAN YOU DO TO HELP?

- Spread the word!
- Many people with bleeding disorders were exposed to hep C. Have you ever been tested? If you used factor before 1993 – even as a baby – you could be at risk. Act now – if you don't know whether you have hep C or not, get tested!
- If you have hep C, talk to your doctor about treatment that could cure your hep C.

WHAT'S STOPPING YOU FROM TREATMENT?

If you or someone you know with a bleeding disorder and hep C has something that is getting in the way of treatment, we invite you to speak to your Foundation or your Haemophilia Treatment Centre to find a solution together.

MORE INFORMATION

- HFA Hep C treatments page - <https://tinyurl.com/new-hepc-treatment>
- World Hepatitis Day page - <http://www.worldhepatitisday.org.au>

A NEW STRATEGY FOR REDUCING STIGMA & DISCRIMINATION

HFV staff were delighted to attend the 2017 Department of Health & Human Services BBV Forum.

Minister for Health, Jill Hennessy, launched the new HIV Strategy 2017-2020. It is the first time that reducing discrimination stigma and discrimination has been a key component to the strategy.

On page 12, HFV member Anthony McCarthy shares his story and own journey to help reduce stigma and discrimination within the community.

Media Release

The Hon Jill Hennessy MP
Minister for Health
Minister for Ambulance Services



Wednesday, 28 June, 2017

BOLD NEW PLAN TO ELIMINATE HIV IN VICTORIA

The Andrews Labor Government has unveiled a bold new plan to develop a cure for HIV, backed by more than \$1 million in new funding.

Speaking today at the fifth annual Blood Borne Virus and Sexually Transmissible Infections Forum, Minister for Health Jill Hennessy launched the *Victorian HIV Strategy 2017-2020* – a roadmap to the virtual elimination of new HIV infections by 2020.

The plan sets out the Labor Government's strategy to improve prevention, testing and treatment of HIV, and work with affected communities to reduce HIV stigma and discrimination.

Its key targets are to have 95 per cent of people with HIV diagnosed, accessing the best treatment, and achieving undetectable viral load by 2030. It also seeks to eliminate HIV related discrimination and stigma completely.

The ambitious Labor Government plan is backed by \$1.2 million in funding, to find a breakthrough cure for HIV. In addition, a statewide Testing Week for sexually transmitted infections and blood-borne viruses in Victoria will be held in the second week of September.

It's the first time an initiative of this kind has been held in Victoria, and will boost education about the need for testing and rates of people being tested.

In Victoria, HIV continues to disproportionately affect gay, bisexual and other men who have sex with men. Removing the stigma and discrimination from Victorian laws, services and society is a key component of the HIV strategy.

For the first time in Australia, the plan also acknowledges women, trans and gender diverse people as priority populations.

The Labor Government is continuing to expand access to the life changing HIV prevention medication PrEP, which evidence shows to be up to 99 per cent effective in preventing HIV infection.

The *HIV Strategy* was developed with the support and expertise of the entire sector including researchers, clinicians, healthcare professionals, community and grassroots associations and people living with HIV.

Quotes attributable to Minister for Health Jill Hennessy

"We are determined to rid Victoria of HIV, and the discrimination and stigma it causes."

"We are setting the bar high. Our bold plan will see Victoria beat targets set by the UN for the virtual elimination of new HIV infections across the world."

"The strategy is backed by more than a million dollars in funding to help us finally develop a cure for HIV."

Media Contact: Crys Ja 0434 367 449 | crys.ja@minstaff.vic.gov.au

Reflecting on our lives with HAEMOPHILIA

A HUGE ACHIEVEMENT FOR ADAM & VERY PROUD MOMENT FOR HIS FAMILY

Hi my name is Adam, I am thirteen years old and was diagnosed with severe haemophilia at 7 days old when I became very unwell after having an intracranial bleed at birth.

For me to live my life as normal as possible and reduce the risk of having painful bleeds in my joints I need to have my Factor 8 medication administered by a needle into my veins every second day. Usually my mum would give this to me in the morning before I head off to school. However, I made a promise to myself that when I became a teenager I would do this.

Anytime I have been away from home for two days or more my mum has had to meet me to give me my Factor. My mum even had to come to my Canberra school camp with me. I find it embarrassing that I cannot be "normal" like the other children.

On Sunday June 4th 2017 I decided I was going to change this and give myself my Factor. I was very nervous as I thought I might not be able to find my vein. My left hand is a little shaky, so not good with a needle. Mum said to me "take a deep breath, take your time and you know your veins better than anyone else". I picked up the needle and inserted it into my arm finding my vein the first time and I gave myself my Factor. I smiled at Mum and said "I got it" and I was happy because I knew that now I can do more things for myself and I had become a little bit more "normal".




LADIES DAY 2017 CANCELLED

Unfortunately, due to low numbers the 2017 Ladies Day will be cancelled for this year. Due to numerous other events including the Conference and Red Ball we are unable to reschedule the date for 2017. We encourage all our HFV ladies who would have attended the Ladies Day to attend to our Christmas Picnic. This will be a wonderful opportunity for you to connect with many other members, committee and staff.



Understanding Ambulance costs

...what does it mean for you?



Do people holding a Health Care Card or Pension Card covered for ambulance transport

Under the State Concession Scheme, eligible Victorians holding certain concession cards receive free clinically necessary ambulance coverage throughout Australia. In all cases, transport is provided to the nearest and most appropriate medical facility.

For the purpose of ambulance transport, the Concession classification includes:

- a person holding a current Victorian Pensioner Concession Card (includes dependent children listed on the card but not spouses)
- a current Health Care Card holder and their dependents including spouses listed on the card (does not include Health Care Card for carer allowance and foster care issued in the name of the child)
- a child holding a current Child Disability Health Care Card or Foster Child Health Care Card, but not their guardians/families listed on the card
- a child under a Family reunification, Care by Secretary or Long-term care order including children on interim accommodation orders
- a person who is subject to an order under the Mental Health Act 2014, Sentencing Act 1991, or Crimes (Mental Impairment and Unfitness to be Tried) Act 1997 requiring them to be compulsorily assessed or treated in a designated mental health service. This includes compulsory, security and forensic patients.
- asylum seekers who are clients of one of the 16 nominated agencies for asylum seeker support found here Ambulance Transport Payment Guidelines

Concession transport from a private healthcare facility:

If a concession card holder is trans-

ported from a private healthcare facility the sending private facility is responsible for payment. This includes registered private hospitals and registered private day procedure centres. The private healthcare facility decides whether or not to pass this cost onto the patient.

Concession benefits do not apply when:

- a patient only holds a Commonwealth Seniors Health Card and they do not have one of the concession cards listed above
- a patient requests to be repatriated or relocated to or from Victoria for non-clinical reasons or when the transport is not clinically necessary (repatriation back to Victoria must be authorised as clinically necessary and there must be a demonstrated clinical requirement for ambulance transport)
- another party is responsible for the account.

The other party responsible could be:

- the Department of Veterans' Affairs (DVA) where a person holds a Gold Card or a White Card (subject to the conditions of the card)
- the Transport Accident Commission (TAC) (subject to the conditions under the scheme)
- the Victorian WorkCover Authority (VWA) (subject to the conditions under the scheme).

Evidence of concession entitlements
In order to access entitlements, AV will require evidence of concession entitlements. The card must also be valid at the time of transport or the account will remain the responsibility of the relevant individual, hospital or chargeable authority as detailed in the Ambulance Payment Guidelines.

What about Private Health Insurance

Ambulance Victoria have no affiliations with private health insurers therefore we have no knowledge of a person's individual coverage through that fund. Please also be aware that when you take out ambulance cover with a private health insurance company they do not purchase genuine Ambulance Victoria coverage through us on your behalf. Private health insurers set their own terms and conditions of what they will and will not cover.

Sadly, we see cases every day where members of private health funds have used the service and then found out that the fund's terms and conditions do not cover them in particular circumstances, such as air ambulance transport or non-emergency transport

Ambulance Victoria recommends you contact your fund and use the Ambulance Cover Checklist as a guide to determine if you have sufficient ambulance cover.

For total confidence and peace of mind that you are fully covered, it is recommended that you maintain your genuine Ambulance Victoria Membership.

Note: Ambulance Victoria is not 100 per cent government funded so membership fees are a vital source of funding. All membership fees are directed back into operating and improving our services as opposed to revenue obtained by your private health fund which is not forwarded to Ambulance Victoria.

For more information, please go to Ambulance Victoria at www.ambulance.vic.gov.au

Note: HFV provides Ambulance subsidies for current members

2017 **BLOOD BROTHERS** ACTIVITY

HFV are currently finalising the 2017 Blood Brothers Activity.
We anticipate this will be held in **EARLY DECEMBER**.

All previous participants will be contacted prior to the event, however **we would love to see some new faces there** so if you would like to be notified about the event please contact our office on 03 9555 7595 or email julia@hfv.org.au
This will ensure you receive all the info in plenty of time.

Help support HFV through Entertainment Book or Digital Membership online at www.entbook.com.au/1834x75

FREE MOVIE TICKETS OFFER

Memberships purchased through the HFV payment page (www.entbook.com.au/1834x75) from 1st September until mid September will receive 2 movie tickets
-check the Entertainment Book website for more details



The 2017 | 2018 Entertainment™ Memberships
are now available!

Change to **MyABDR Remember Me** function

From the National Blood Authority and HFA MyABDR teams

From Tuesday 22 August 2017 if you want to use the REMEMBER ME function on the MyABDR app, you will need to set a 4-digit pin.

To set the PIN, at the login screen tap the REMEMBER MY DETAILS button NOT LOGIN.

WHY HAS THIS CHANGE OCCURRED?

You may be aware of the current concerns at a national level about the protection of personal information.

Protecting ABDR/MyABDR users' personal information on mobile devices and computers, while preserving favourite functionality has been a subject of considerable discussion between the National Blood Authority and HFA.

Against this background the NBA has implemented a simple solution of a four digit pin lock to access MyABDR on your mobile device.

This solution is only required when accessing and using MyABDR and does not impact on the use of your mobile device. The pin lock is very similar to other applications such as online banking.

The enhancement to the 'Remember my details' functionality means that you can continue to use this option knowing that your access to the ABDR/MyABDR system is now more secure.

HOW WILL THIS WORK?

- When you tap the REMEMBER MY DETAILS button at the LOGIN screen, you will be invited to set a 4-digit PIN.
- Whenever REMEMBER MY DETAILS is activated, you will need to use your 4-digit PIN to login if you have not used MyABDR in the last 30 seconds.

- However, when you are logged out and need to login again, you will still need to enter your email and password – BUT!!

- If you want to use the 'remember me' functionality, you should tap on the REMEMBER MY DETAILS button rather than LOGIN to login, and then set or reset your PIN.

OTHER SECURITY IMPROVEMENTS

The National Blood Authority rolled out the new PIN functionality with other security improvements in the MyABDR release on 22 August 2017:

- Security improvements to the website version
- New messages on the mobile app where the device is insecure
- MyABDR will no longer be accessible from 'rooted' or 'jail broken' devices.

ANY QUESTIONS OR NEED HELP?

Contact the MyABDR Support team (24 hrs, 7 days a week)

T: 13 000 BLOOD / 13 000 25663

E: support@blood.gov.au.

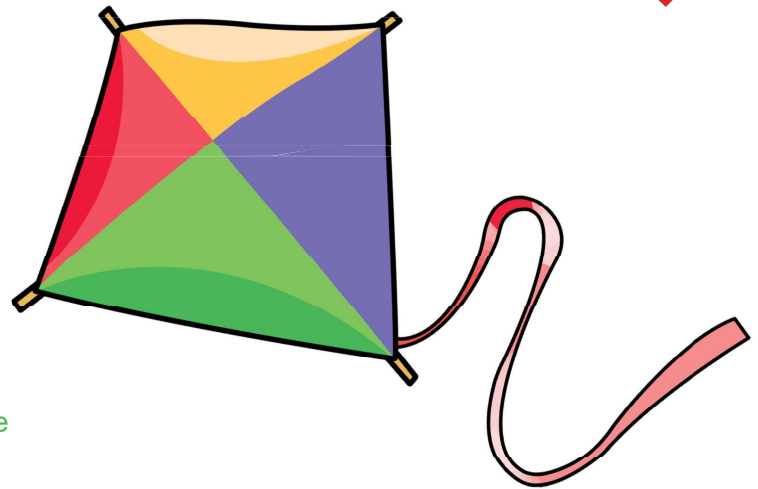
ANNUAL GENERAL MEETING CHRISTMAS PICNIC &

BYO PICNIC & KITE...or
make one on the day!

Please come and join our HFV committee and staff for our Annual General Meeting and Christmas Picnic.

This year we are heading to Royal Park Nature Playground. The playground has been built on the site of the old Royal Children's Hospital so we are sure it will be of interest to many of our members who would have spent much time at the old hospital.

A fantastic new playground with natural play elements including an area of high rope traverses, large climbing structure made from logs and ropes, water play area and landscaped areas. The playground is located immediately to the east of the Royal Children's Hospital and provides a wonderful resource for patients and visitors to the hospital.



AGM

At the AGM we will be electing our committee. We are always looking for new members to join our committee. If you are interested, please complete the enclosed nomination form or call the office and speak to Andrea about what is involved!

WHEN: 11.00am - 2.30pm Sunday 19th November
(AGM to be held at 12pm)

WHERE: Royal Park Nature Playground,
Cnr Gatehouse Street & Story Street, Parkville, Vic

BYO: Picnic & Kite - or make one on the day
(Kite making materials provided by HFV)

PARKING: There is free parking available and street parking

BOOKINGS ESSENTIAL THROUGH THE HFV OFFICE ON 9555 7595 OR andrea@hfv.org.au



REGISTRATIONS NOW OPEN



18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October 2017

The 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders will be held at the Pullman Albert Park, Melbourne, 12-14 October 2017.

The theme for the conference is “**Looking Forward to Change**”.

Over the past 37 years, we have been running conferences that provide current information and resources, discussion on topical issues and looks into the future.

Our Conferences 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, discuss and to plan for the future.

The program covers current topics and issues to interest everyone including:

- new treatments for haemophilia
- using data to improve treatment and care
- women with bleeding disorders
- genetic testing
- living with von Willebrand disease
- new approaches to managing pain
- HIV and hepatitis C
- living with a bleeding disorder at different life stages - newly diagnosed, children, adult life, ageing
- issues for families and siblings
- youth matters
- sport and healthy activities
- what is the future like

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 in Melbourne!

Gavin Finkelstein
President
HFA

Deon York
President
HFNZ

Dr Huyen Tran
Program Chair

**It's not too late
to register...**

[www.haemophilia.org.au/
conferences](http://www.haemophilia.org.au/conferences)

HFV MEN'S FISHING TRIP

4am - 10am on Tuesday 28th November

St Kilda Pier - Private Fishing Charter
on the 'Bella Sandro'

Join Neil Boal and other guys with haemophilia for a great morning fishing on Port Phillip Bay



- The charter boat caters for people with mobility issues.
- Fishing licenses are required and can be purchased on the boat for \$10.
- Sausage sizzle and refreshments provided and your catch cooked upon request.
- The event is heavily subsidised by HFV. A contribution of \$50 per person is required on the day.
- Parking is available at St Kilda Sea Baths for \$14 per day. This event is for members aged 18+
- **Bookings are essential through the HFV office on 9555 7595. Book early to avoid missing out!**

HFV Noticeboard

To post a message on our noticeboard, please email our HFV office at info@hfv.org.au or call 9555 7595

APPRECIATE A VISITOR?

We are a few guys with haemophilia and we have all spent enough time in hospital ourselves to know that a visitor can really boost your day when you've been admitted. We would love to make ourselves available to break the feelings of isolation or loneliness we sometimes feel on the ward when you are away from the familiarity of home.

As volunteers from HFV we would be available visit anyone from our community with your permission that has been admitted to The Alfred. We all live or work near to The Alfred so one of us could easily drop in.

We are currently going through the steps to become official 'visiting volunteers' at The Alfred so hope to be set-up within the next month.

Please get in touch if you or someone you know would benefit from a visit by contacting the HFV office directly on 03 9555 7595 and the staff will contact us.

Zev, Dan & Anthony - HFV Members

INHIBITORS

It can be a very challenging time if your child has inhibitors. If you would like to talk to another family who has been through a similar journey please call the HFV office and we can put you in touch.

Call 9555 7595.

RED RECIPES NEEDED

Donna Field is coordinating a Red Recipe Book for Bleeding Disorders Awareness Week. If members have any recipes with a red theme or ingredient, please email them to d.field@bigpond.com and include where the recipe is from ie Donna Hay or family recipe. Any recipes that aren't used this year will be included in a more substantial book next year! Thank you.

LADIES DAY **CANCELLED**

See page 15 for more information

diary dates

SEPTEMBER

9 ~~Ladies Day Out~~ CANCELLED

OCT

8-14 Awareness Week 2017 -
Check HFA for further details
www.haemophilia.org.au

12-14 Haemophilia Conference
Melbourne

20 Haemophilia Red Charity Ball

NOV

19 AGM & Family / Community
Christmas Picnic

28 Men's Fishing Trip

DEC

TBC 2017 HFV Youth Event

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

WANT TO BE INVOLVED?



You can contribute to the project by joining the HFA women and girls review groups:

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

Suzanne at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173.

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

Website: www.hfv.org.au

Fax: (03) 9555 7375

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 2016 twelve 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.

Friday 20th October 2017

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

Dress Code - Formal with a **touch of red**

The Haemophilia Red Charity BALL

ONLY 6 WEEKS TO GO until THE HAEMOPHILIA RED CHARITY BALL and it is set to be an amazing night! Tickets have sold incredibly fast with only a very limited number of tickets still available.

We are overwhelmed by the generosity of our community and friends. We already have an amazing selection of donations to be auctioned on the evening which include:

- Original artwork
- A bicycle
- Signed football jumpers (Melbourne, Collingwood, Carlton and Essendon)
- Signed Melbourne stars cricket bat
- Bed and Breakfast voucher in the Yarra Valley
- Port Fairy accommodation and meal vouchers
- Delta Goodrem perfume and CD signed by Delta

HOW CAN YOU HELP MAKE THE NIGHT A HUGE SUCCESS?

- We are seeking "experiences" to auction off on the night... do you have any connections which could lead to items which can't otherwise be bought being donated? For example, backstage passes to concerts or theatre productions, corporate box seats to events, meet and greet with a celebrity or sports star etc

- We are seeking samples for our guest goodie bags. Do you have any connections to companies which may be willing to supply at least 100 samples of creams, perfumes or beauty products?

PLEASE SEND US YOUR PHOTOS!

- We need your photos to help us raise money at The Haemophilia Red Charity Ball. We are looking to showcase as many kids and youth as possible in a slide show highlighting some of the challenges of haemophilia. In order to pull at the heartstrings and loosen those purse strings we need photos of our kids having their treatments, photos of their bumps and bruises, at hospital visits or on crutches...things we don't always see and could help people understand that despite wonderful treatments for haemophilia it is not always plain sailing.
- If you can help, please send your photos to julia@hfv.org.au. Thanks for your support!!!