

# THE MISSING FACTOR

My  
'WARNING'  
label

**SURVIVING  
THRIVING**

**SHAPING OUR  
FUTURE DOCTORS**

connect • support • empower





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Walk for Bleeding Disorders

## NOV

17

AGM & Christmas Picnic at Melbourne Zoo



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

# PRESIDENT'S REPORT

Time to get out the winter woollies and snuggle up with a good book or is it a kindle these days? Winter is here but the work at HFV continues.

We are all feeling pleased after another very successful Community Camp and Men's retreat. It is a special time for us all when we can get out and spend time with our members to hear about your challenges and the issues that impact on you. Attending these events always reminds me of the very special people we have within our community and an opportunity to celebrate life despite the challenges.

One of the many benefits of our events is the connection with those amongst us that inspire us in their dedication and achievements. We were fortunate to have nearly all the members of our amazing fund-raising subcommittee with us. This provided an opportunity to discuss the next ball! Wow! It is already shaping up to be amazing so get on board with your support. If you know a company that can donate, or have a few hours free to make some calls to request donations we want to hear from you. Jump on board early to be a part of the fun. An amazing effort last time so if you missed it make sure you are part of the 2020 celebration.

We are looking forward to our regional visits that are planned. Again, we have chosen a couple of areas that we have not been before in the hope to connect with new people. However, catching up with all members is the goal so please check the dates and see if you can join us. Both the staff and committee are committed to getting out and about and appreciate your support in coming along. HFV are working closely with HFA in an exciting project that is researching the impact of ageing with

Haemophilia. There is more information on page 5 so if anyone in your family are interested in being involved please contact the office to discuss further.

Peer support continues to be one of our priorities. Apart from camps we also host day events. Sadly, in recent times we have had to park the Grandparent support events while we find a new convenor. If you are interested in supporting this work, please contact us. It is a small commitment of time with many benefits. We know often the grandparents or older support networks are the glue for families to be able to cope with the busy life imposed on us all. The social gathering is our way of acknowledging and thanking these important people in your life so if you can assist with this, we would love to hear from you.

We are also working on some longer-term planning on the youth leadership programs. We know the youth of today are the future of HFV for tomorrow. There will be some strategic planning looking at the needs of HFV from here to five years with the hope we can engage those critical leaders to be ready to support the work of the future. If you have any experience in engaging with youth or others that may be marginalised, we would love to have you on board as part of the think tank. There are so many diverse and skilled people within our community we would love to hear from you with fresh ideas. Young or old I am sure your ideas will be welcomed and add value to this important piece of work.

We are also currently working on a detailed membership engagement survey. Erika Mudie has a great deal of knowledge in this area and is currently working on producing a survey that will provide an in-depth understanding on our current

engagement. We look forward to your participation on completion.



Again, I take this opportunity to acknowledge the tireless work of HFA. As our national peak the team led by Sharon do amazing work to advocate for the health options we enjoy. During times of changes to products and treatment options the role for all of us in advocacy is critical. As many of you have heard from me on many occasions, our strength as an agency sits in our collective voice.

**By being a financial member and supporting the work of HFV you are also supporting the imperative work of HFA at a national space.**

Our heartfelt thanks to all their amazing work and we value the collaborative space that we work together in achieving the extraordinary for our shared community.

Some of you may recall I was very lucky to go to Myanmar to represent HFA in an exploration visit to see what could be achieved in supporting their community. Still early days and I will update you all in the next magazine.

Stay warm. Stay well. Stay connected. Look forward to seeing some at our regional and outer metro roadshow or as always welcome a call or visit from any members especially if the challenges of life mean you could do with a bit of support. We have all been there and are here to lend the support when it is needed.

Leonie Demos



# SURVIVING THRIVING



*We've just arrived home from the 2019 HFV Community Camp. This was our fifth camp, and as always we had a great time, challenging ourselves with the outdoor activities as well as catching up with all the friends we made on previous camps, and meeting new ones as well. One thing, however, stands out with me from this camp that I want the rest of the HFV community to know about. This morning we did an activity that everyone at camp took part in, raft building. Some interesting things happened.*

*We split into three raft building teams, as well as having a great deal of onlookers and supporters. Each team had the same limited amount of equipment from which to build their raft.*

*Firstly we had to negotiate within*

*our teams how we would design our rafts; where to position the floats, where to position the planks, and how to keep them together with the limited number of ropes. Not everyone agreed, compromises were made, and before long three rafts were built. Like their names, Connect, Support, Empower, each raft was different. Crews of four from each team then had to test each raft on the lake, and although none were perfect, and some parts seemed to be not-so-well attached, all the rafts individually were a success.*

*Now is when things really get interesting. The three individual rafts needed to be combined to create one super-raft. Some clever thinking by the now combined super-team (and a few extra ropes), soon had the super-raft, aptly named Surviv-*

*ing Thriving, being tested for seaworthiness. How could we be sure that Surviving Thriving would support everyone? The only logical way, by everyone testing it! Yes that's right, everyone at camp, not just the three teams. The test was a success, and it was declared that Surviving Thriving could be trusted. In fact it seemed that the combined super-raft was stronger than any of the three original rafts alone, even though none of the original rafts were modified or rebuilt to form the super-raft.*

*Surviving Thriving then set sail on its maiden voyage, all the way across the lake and back, which may well be a new camp record. Well done everyone!*

**Lindsay Parker**

# FUTURE PROOFING

Hands up if you're getting older?



## ***Preetha Jayaram is the HFA Getting Older Project Officer***

Is future proofing an important aspect of the health and wellbeing of bleeding disorders community members?

I took up the position of Project Officer at HFA in February 2019 and, as a first step in the project, have been looking into the needs of people with bleeding disorders in the future. This has involved consulting with community members, state and territory foundations, medical specialists, haemophilia nurses, psychosocial workers and physiotherapists to explore current issues and how to 'future proof' as people grow older.

Getting Older is a priority project of HFA. The project aims to identify, understand and respond to the range of needs people with bleeding disorders may have as they are getting older and help find appropriate solutions for them and their partner/family or friends/carers.

In the second stage of the project we will look at some

solutions to enable people in the bleeding disorders community and their partner/family to manage their health and wellbeing into the future as they grow older. These will be taken from the recommendations in the needs assessment. To reach the community in this digital age, this will include online options for community members to inform themselves and connect with each other. This may involve, for example, expert information about exercise with arthritis or travelling as you get older. It will be important to give a voice to men and women – both people with bleeding disorders and partners/family or carers - so that they can share thoughts about what is needed and the strategies and services they have found useful. It may also involve strengthening current peer support groups.

I am looking forward to speaking with bleeding disorders community members and their partners/family around Australia to hear the issues they see around 'future proofing' their lives.

**If you are interested in sharing your thoughts about 'future proofing' and getting older with a bleeding disorder, please contact Preetha Jayaram at HFA to talk about your availability.**

**Partners/family also welcome.**

**Phone: (03) 9885 7800  
Email: [PJayaram@haemophilia.org.au](mailto:PJayaram@haemophilia.org.au)**





# So...I guess I should tell you about my WARNING LABEL

'So...I guess I should tell you about my warning label,' Dan said towards the end of our very dreamy first date.

Have you ever had those "record scratch" moments in life? This was one of those for me. Until that point my only frame of reference to imagine anything like a warning label on a person was The Girl with the Dragon Tattoo in which the heroine tattooed one of the villains in the story. I'll spare you the gory details if you haven't seen it, and if you have seen it, you'll know what I'm talking about.

Then I became quite aware of my surroundings. Despite it being only 10pm and though we were walking along one of Phnom Penh's main roads, there wasn't anyone around that could help me if this situation got creepy...er?

Yet, I decided not to flee. 'Warning label? Tell me more,' I said.

'It's quite lengthy,' he said as I continued to catastrophise in my head. 'It's ugly, too.'

'Metaphorically or literally?' I asked.

'It's a tattoo on my ribs that explains my medical condition in seven languages. I'm a haemophiliac,' he said.

'Oh, cool!' I said, too enthusiastically. Perhaps because despite not having any experience with either haemophilia or criminal activity, a genetic mutation that causes your blood not to clot seems like the lesser evil.

Eventually, I got to see this tattoo, and...I wish I could tell you he was lying when he said it's ugly, but he wasn't. Apparently it's lack of finesse is a result of it being done quickly because he had to take extra doses of his medicine to get it and wasn't interested in making multiple visits to perfect it.

'It's utilitarian,' he explained. 'I got it in case I get in an accident and don't have my medic alert on me, the first responders will know I have this condition. Makes more sense to have it on my torso in case I lose a limb.'

As dating turned into a serious long distance relationship, as that turned into us being engaged and now that we're married the warning label has become less of a novelty. Over time I've come to see it as an externalisation of what's otherwise an invisible part of Dan's life, a part of his life that can turn things ugly at times.

As our lives meshed I got used to Dan's bi-weekly infusion ritual. The World War II docu-

mentary would be queued up on YouTube. The vials of protein and tubes of saline would come out and I'd busy myself around him and try not to think of how much our bodies spontaneously bleed.

His left elbow doesn't have full extension because he didn't always have prophylaxis available to him. As a child, growing up in the 80s, he had to take days off school to receive transfusions of human blood to treat any bleeds that showed up in his joints. And those transfusions gave him Hep C. His teachers would pull his sisters aside at school and ask if their parents were physically abusive because he always



had bruises on his legs.

Haemophilia's made so many things impossible for him like joining the Air Force, or – at times – even his attendance at parties. It's slowed down many other things he's gone for like getting medical clearance for his pilot's license, or getting a spouse visa to live here.

But all of these ugly things gave him beauty in my eyes.

He's got humility and gratitude because he knows so many haemophiliacs ended up with HIV and died of AIDS because of those blood transfusions and he eventually eradicated his Hep C, while many others didn't.

He knows he was lucky to be born into a family that could afford for a parent to take the time off work for his hospital visits so he was never made to feel like this is a burden, which gave him the confidence to skydive, live in developing countries, fly planes and drive motorcycles. You know, doing things that generally aren't encouraged, but haemophiliacs are especially warned off of.

He has endless patience because he spent so much time just sitting and getting treatment. And explaining that 'No, I'm not going to die from a single paper cut'. He understands how to judo with bureaucracy because a lot of insurance paperwork comes with this condition.

For the past seven years I've been the beneficiary of these wonderful traits and I will be for many more years to come as life happens and other challenges come up.

It's easy to love what's normal, what's beautiful. But there are gifts that come from embracing the unusual and the ugly. With my husband, beauty really is more than skin deep, it's chromosomal.

**Erika Mudie**  
**HFV Committee Member**

# Sharing YOUR story

*At HFV we are very proud of our young members, how they participate at camp, are considerate and caring individuals and often see the bigger picture. Lachy Parker is one of these individuals and has kindly shared his leadership speech prior to him being appointed school captain!*

## LACHY PARKER

"A leader is the one, who knows the way, goes the way and shows the way."  
- John C. Maxwell

My name is Lachlan Parker and I'm running for a captain role in 2019. I believe that I will have a positive impact on the school community at St. Mary's. My leadership qualities will have a good influence on the younger generations, my fellow peers and teachers here at St. Mary's.



Some leadership qualities that I have are thoughtfulness for others, I strive to always do my best, and help others when they are in need. I believe I will be a great leader because I am supportive, optimistic and respect my peers, teachers and the school community.

I was born with a rare bleeding disorder called haemophilia. By having haemophilia I have gone to camps with others boys with this disorder. By going to these camps I have learned multiple leadership skills. At these camps I have learnt that no matter how different you are you can still achieve greatness. I may not be able to make you a millionaire but it's the little things that count and can make you a leader.

With this position I will keep striving to be the best person I can be and better. So be your best and do those little things to be a leader. So do a little thing for me, and vote.

Lachlan Parker.

CONNECT SUPPORT EMPOWER

# HFV 2019 Ladies Day



JOIN OUR HFV LADIES FOR A  
FOOT OR NECK/SHOULDER  
MASSAGE FOLLOWED BY LUNCH

**SATURDAY 27TH JULY**

10.30 - 2.30 True Thai Massage  
399 Chapel St, South Yarra  
followed by lunch at Peppans  
(\$10 donation suggested)

BOOKINGS ESSENTIAL (limited places)

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



# 2019

## Reflections on the MEN'S RETREAT

*To all at Haemophilia Foundation Victoria,*

*I'd like to send my heartfelt thanks for the weekend retreat, and let you know I thoroughly enjoyed myself at Carisbrook. From the superbly relaxing massage to the incredibly warm hospitality that Sharon and her team showed us. I can't speak highly enough of Sharon. Her kindness seems to know no bounds and she anticipated many of our needs and could not have been more attentive.*

*And very valuable to me was the humour that we shared right through, and having the time and space to have proper meaningful conversations with my peers, some of*

*whom I hadn't met before. The more time I spend with my haemophilia mates the more I admire them. I came away, again, with an amazing feeling of belonging to a very special community of men. Men who have endured great physical pain and mobility challenges and in some cases, life-threatening viruses. But we all seem to share a joyful capacity to enjoy life and laugh at ourselves. I'm very grateful!!*

*Warmest regards,  
Anthony*



# PROBE FOR REAL-WORLD EVIDENCE



## The real-world PROBE study is now available!

What is the impact of haemophilia and treatment on Australians?  
How can we have access to high quality evidence about this?

With new treatments becoming available this kind of evidence is particularly important. We need to be able to explain what it's like to have haemophilia and the impact of different types of treatments. HFA's advocacy relies on credible data. Without this data we have not had enough strong evidence to use in our advocacy for new treatments.

The **PROBE (Patient Reported Outcomes Burdens and Experiences)** study is a great opportunity for you and others in our community to give this evidence.

### What is PROBE?

PROBE is a multi-national research study ([www.probestudy.org](http://www.probestudy.org)) which allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. It compares their answers to other people in their community who do not have a bleeding disorder.

**You may have done the PROBE survey in the past. This was testing the survey.** In 2015 Australia joined more than 20 other national haemophilia organisations around the world to successfully test and validate the questionnaire. The international

PROBE team is led by well-respected haemophilia organisation and academic investigators.

### ***This time the PROBE study is collecting real-world evidence.***

Statistics from Australians who complete the questionnaire will be provided to HFA by the international team for us to use in our advocacy and planning for the future.

### **HOW CAN YOU HELP?**

You are invited to complete the questionnaire if you are **an adult (18 yrs+) who lives in Australia** and:

- **Have haemophilia or carry the gene OR**
- **Do NOT have a bleeding disorder.**

You may also like to pass the survey on to your partner/wife/husband or other members of your family or interested friends.

**We need a few hundred Australian participants for good quality results, so the more people who complete the survey, the better!**

### **How to do the survey**

The questionnaire is available:

- **Online** at <https://stage.mcmaster.plus/PROBE/>
- Or ask **your local Foundation** or **HFA** for a print survey pack

### **What happens to your data?**

All responses are anonymous and confidential. They are combined as statistics and will not identify individuals. The survey is voluntary – it is up to you if you want to complete it and no one will know if you have or haven't.

### **More information**

For more information about the **PROBE study in Australia**, visit [www.haemophilia.org.au/research](http://www.haemophilia.org.au/research)

Or contact Suzanne at HFA:  
[socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)  
1800 807 173



# STEPPING UP AT HFV

## Supporting leaders...

## FOR THE FUTURE

This year we were very fortunate to have 3 new Youth Leaders attend our camp, Dylan, Marc and Jake. We are very proud of our affectionately known 'Blue Shirts'. Our Blue Shirt leaders are carefully selected from our community camp youth members as those who show key skills such as leadership qualities, compassion, encouragement. However, this year Dylan, Marc and Jake, whom had all previously connected with HFV through youth initiatives, put their hands up to be youth leaders 'In Training' to help with the running of the program. We feel so fortunate that these three young people value our community enough to want to step up and offer their support to assist our community without ever experiencing it themselves. To turn up to camp on your own would be daunting for many but these young men stepped up and proved to be wonderful examples for our younger aspiring blue shirts and our entire community.

It was wonderful to see these young men making connections with our members and engaging with the whole community. We hope they remain engaged with HFV for the future as they have so much to offer. Dylan has shared his thoughts with us about his camp experience below.

*Growing up with haemophilia, I always felt like a little out of place with everyone else. It was kind of hard to fit in when you're always in hospital, or suffering from a joint bleed or the million other little things we've got to deal with every day.*

*One thing that always helped me was the Haemophilia Foundation. Sometimes when I was at the Royal Children's and now The Alfred, I would find an opportunity to have a friendly chat with their charming staff members about my journey or how I could be more involved helping in the community.*

*That's why I'm so grateful to Julia and Andrea and the team for giving me the opportunity to become a Youth Leader at the 2019 Community Camp, I'd definitely say it was one of the most rewarding and awesome experiences of my life. I not only got the chance to connect with more HFV members and their families but I also got some valuable tips from other campers and*

*the volunteers on how I can deal with my haemophilia more efficiently.*

*However, something that struck me far more deeply was being reminded by campers, Foundation members and the Purple Soup gang was that no matter what might happen with our conditions, you'll always have a community behind you who have seen it all before and will stand by you no matter what.*

*If you feel nervous about joining in for the next event, I encourage you not to be. If you give them a chance to help, they can always make a difference and you're guaranteed to meet plenty of life time friends.*

*I hope to see you there,  
Dylan*

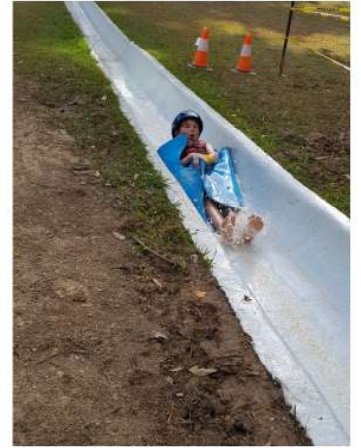


*Dylan testing out his trampolining skills during some down time!*

The HFV committee are doing some planning on the future of youth leadership programs. Supported by Ben Inglis, who plays a significant leadership role, we are working on formalising some of the future plans to ensure that the leadership program strengthens and grows. HFV welcome any young people from our community including siblings and extended family to join in to these discussions and be a part of HFV's future.



# HfV Community





# Camp 2019!

Join us  
next year!





# WORLD HEMOPHILIA DAY

17th April 2019

LIGHT IT UP  
**RED!**

World Hemophilia Day is celebrated every year on the 17th April. For the last few years there has been a world wide initiative to LIGHT IT UP RED with over 70 landmarks participating globally! We have been very fortunate in Australia to have many of our major landmarks support our community in raising awareness of bleeding disorders!

In 2019 the World Federation Hemophilia has been focusing on spreading the message that **outreach and identification are “The first step to care”** for undiagnosed people with bleeding disorders. Patient outreach and identification is about finding individuals with hemophilia or other bleeding disorders—including von Willebrand disease—who have not yet been diagnosed, or whose health needs are not being met by healthcare services. These patients can be found through awareness-raising campaigns and educational activities.

Another way our global community has been supporting World Hemophilia Day has been through sharing their stories online. On the following page are stories from our global bleeding disorders community sharing their journeys and challenges of living with a bleeding disorder.

[www.worldhemophiliaday.org/page-stories.php?lang=en](http://www.worldhemophiliaday.org/page-stories.php?lang=en)

We are always looking for our HFV members to share their stories with the community. Peer support does not need to be face to face. Just by sharing your story you can help others to feel they are not facing this journey alone.

**Connect, support and empower  
through peer support!**





Happy World Hemophilia Day! We are working hard in the Research department at the WFH to increase the amount of data we collect on patients with hemophilia and all bleeding disorders. Thanks to all of you who contribute your valuable data to help us improve care around the world.

Data = research = evidence =  
IMPROVEMENTS IN CARE!

Donna - CANADA

I am the mum of a 2 years old boy who has severe haemophilia A. No family history but we know now that I am a carrier.

We are lucky enough to be in that part of the world where we have access to prophylaxis every second day to prevent any bleeds. So far we have had a couple of bleeds, the first big bleed shook our world a little bit as our little man couldn't walk for few days. Haemophilia has changed and shaped our world. At first, I think we were a bit in denial how we will stop haemophilia to rule our world. We were naively thinking that everything will be sorted after a catheter and some treatment. The reality is much more challenging: bleeds, constant worries and we had to become strong advocates for our little man. We are just learning to live with it, one day at the time. We have lost a few friends along the way but we have gained new friends on the way. It made us realise how precious our lives are and we are now learning to surf the waves of haemophilia, sometimes we fall but we always get up again.

Claire - AUSTRALIA

April 17 is World Hemophilia Day. This disorder is near and dear to my heart. I'm not looking for pity but rather to educate on the impact it can have on a persons life and their family. It's much more then just a cut that doesn't stop bleeding. As far as we know, hemophilia started with my dad and he was severe. At a time when they knew very little about it. He spent a good portion of his short life in the hospital. He almost died twice by the age of twelve; suffered many joint bleeds leading to chronic stiffness, arthritis and pain. He died at 35 years of age like most haemophiliacs of that time, due to contaminated blood that he was given that was suppose to help him. For me, growing up as a child I knew I was a carrier of hemophilia and that one day might also have children effected by the disorder. In my early 20's I was diagnosed with mild hemophilia. The bruises, the unexplained ankle injuries,

the heavy menstrual periods, the anemia all finally made sense. Hemophilia complicates a couples decision to have children, the labour and delivery process and in my life the way I raise my children. I was blessed with a daughter with mild hemophilia and a son with severe. We are lucky in Canada. To have access to free healthcare and treatment. Many countries do not, people suffer and some die. Hemophilia is very expensive to treat. I wouldn't change anything in the world for my sweet kids but It means many many clinics appointments, surgeries, hospital stays, 3x weekly IV injections, increased anxiety and stress, safety protocols, stigma, the list goes on. As you can see it's so much more then a cut that doesn't stop bleeding.

Danielle - CANADA

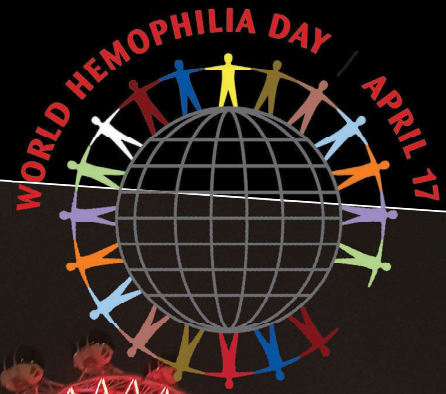
I look forward to the month of April since discovery my first born's hemophilia. He is the first of the family to have the condition. His diagnosis came about a year after his birth. We noticed he got black and blue marks quite easily. I was not really sure what hemophilia was when the word came out of the doctor's mouth and although we were shocked to learn he had severe hemophilia (first tests indicate light), we were at ease once we were told that Brazil provided treatment through the national health system. Recently I was asked how it has changed our lives and my immediate answer was that it added an extra 20 minutes to our morning routine whenever we have to factor up. That is the honest truth, with treatment my 4-year-old leads a normal life, he plays, runs, skates, plays basketball, gets scrapes and bruises, black and blue marks, and busted lips, like any other child - in my phone I collect pictures of these remarkable moments. Last year we found out I was the mutated gene carrier and this year, exactly on April Fool's my youngest (2 months) son also received his diagnosis of hemophilia type A. So, my husband and I are raising two very unique boys. In his words: to have children considered to be "normal" wouldn't have suited us anyhow. I hope future and present parents will realize early on how important treatment is, and will adhere to it earlier rather than later - one should rejoice at the fact that prophylaxis, even if it comes through needle pokes can offer children a more complete childhood.

Joana Bauer - Brazil

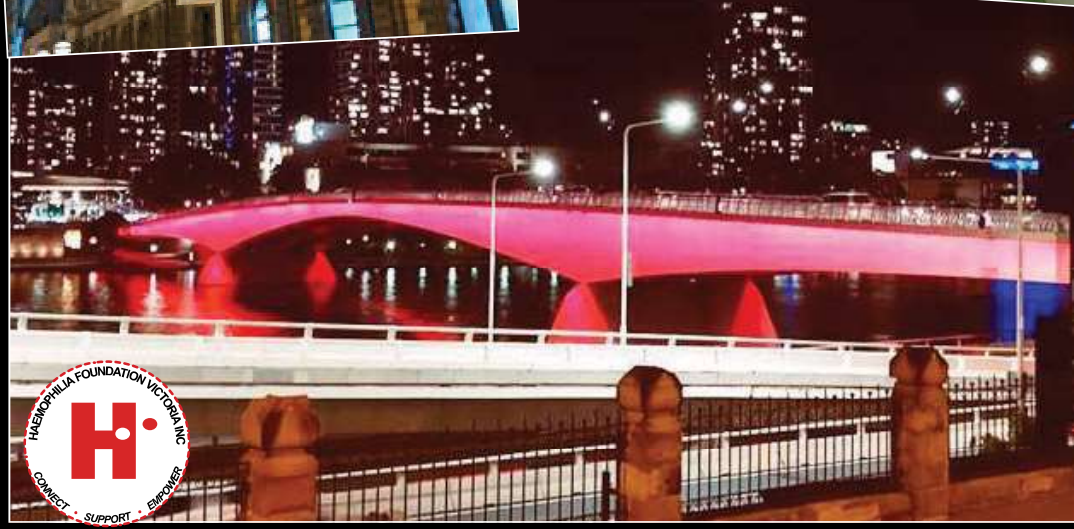
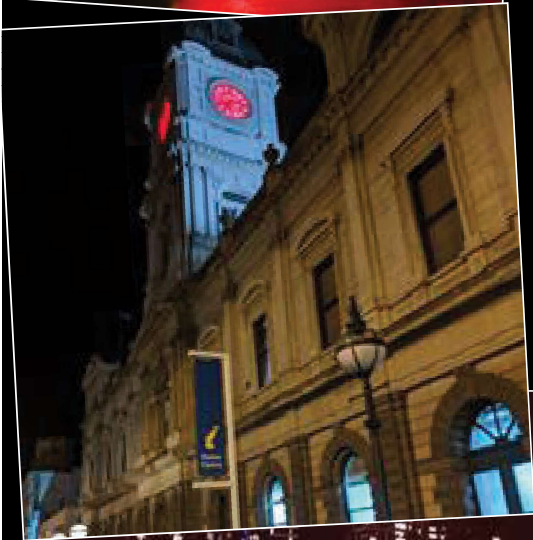
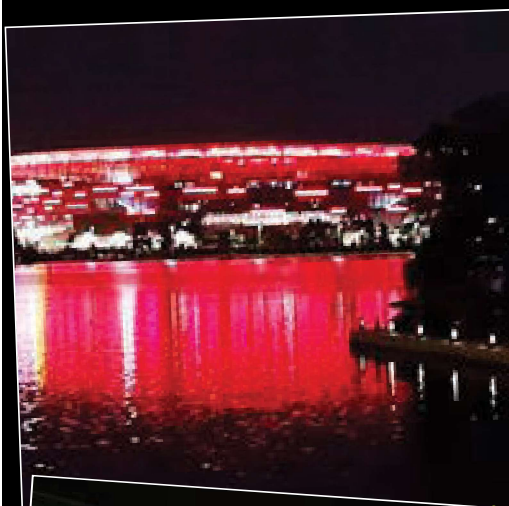
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World Federation Hemophilia

[www.worldhemophiliaday.org/page-stories.php?lang=en](http://www.worldhemophiliaday.org/page-stories.php?lang=en)





Lighting up  
Australia for  
**WORLD  
HAEMOPHILIA  
DAY**  
2019





# Helping to shape our future doctors

Alex Savage is studying medicine at Monash University and is currently volunteering at HFV. He has proved his worth by assisting us in very practical tasks but what has been undoubted more worthwhile to our community has been his ability to connect with some of our community members, hear their stories and get a deeper understanding on the impact of bleeding disorder on families and individuals. Below Alex shares his reflections on his time so far at HFV.

Whilst knowing the chemical reactions behind disorders is necessary for a doctor, it does not make a good doctor. A good doctor understands the disorder on a deeper level – beyond the symptoms and the treatment. A good doctor understands how a disorder affects a person, their family and the community in which they live. As a second year medical student, that is what I would love to gain from my experience with Haemophilia Foundation Victoria.

I study Medicine at Monash University and this year, one of our projects includes volunteering at an organisation of our choosing to develop our knowledge beyond the classroom. This assignment lets us follow one of our interests in medicine to a real world setting, where we can learn about people and families rather than anatomy and physiology.

About 3 months ago, if someone had asked me to tell them what I know about Haemophilia, I would have drawn a diagram of the mechanism by which it affects blood clotting and I would have described the genetics behind this bleeding disorder. If my memory was serving me well, I might have even explained the symptoms and the medications used to treat it. However, this is nothing compared to the knowledge I have already gained from reading personal stories and talking to people and families affected by bleeding disorders. I am particularly interested in three things and I hope my time with HFV can help me

find out more.

Firstly, I believe the history of bleeding disorders is critical to understanding how people are affected today. I was fortunate enough to learn about how the previous failures of treatment will continue to influence the lives of some people with Haemophilia. Even though this was unsettling, it is so important in developing a full understanding of the disorder and, looking to the future to improve.

Secondly, it would be great to understand how social determinants such as strong relationships with doctors, family and support networks have an impact on health. For me specifically, recognising the influence a caring doctor can have on their patients is crucial. Studying at Monash, I have already been given the opportunity to become involved in the community and the most important thing I have identified is how different interactions with doctors can shape someone's outlook on treatment and the health system in general. Talking to more people can only increase my ability to offer the best care in the future.

Finally, until doing some work with HFV, I really didn't consider the role of other organisations in helping families affected by disorders. For me, GP clinics and hospitals were the be all and end all of healthcare. However, I really couldn't have been more wrong! Learning about what peer support networks and other organisations offer and how they are



used in the health setting would be wonderful. It would be great to hear how they affect the community and therefore, how doctors can utilise them to give our patients the best care possible.

Ultimately, a doctor treats people, not disorders. And, even though I cannot have firsthand knowledge of how disorders affect people, hearing stories and engaging with the community will help me be the best doctor I can. I would love to hear from anyone willing to share their story with me.

Please email [info@hfv.org.au](mailto:info@hfv.org.au) if you are happy to chat with Alex.

# PEER SUPPORT WORKS

## Peer support dogs lend a helping PAW to paramedics

More peer support dogs are being recruited to help Victoria's dedicated paramedics deal with the daily challenges they face responding to emergencies and saving lives.

Minister for Ambulance Services Jenny Mikakos announced the expansion of Ambulance Victoria's peer support dog program at a graduation ceremony for new paramedics.

Bruce, the first peer support dog, has made a real difference to the lives and mental health of paramedics who need a helping paw to cope with the traumatic, confronting and life-threatening emergencies they see every day. The affectionate six-year-old labrador has been specially-trained for the role and has made 260 location visits and interacted with nearly 2900 paramedics in a six-month trial.

Up to 12 dogs and handlers will now be trained to help paramedics through difficult moments, reduce stress and deliver better mental health outcomes right across Victoria.

Two dogs, a schnauzer named Callie

and Bernese mountain dog named Lexi, are already trained and ready to help and provide comfort.

The integrated program – the first of its kind for an Australian ambulance service – has also raised awareness of mental health support and reduced the stigma that can at times be attached to seeking help.

A total of 135 paramedics celebrated their graduation, including 127 new paramedics who have recently completed the 12-month Ambulance Victoria graduate ambulance paramedic program – a flagship course designed to support paramedics transitioning from university to the workforce.

The graduating class of 82 women and 53 men also included eight new MICA paramedics who have completed specialised intensive care training.

'Paramedics are front-and-centre in traumatic life and death emergencies and major trauma,' Ms Mikakos said.

'Their job is not easy and it's no surprise that what they see and do can

have a negative impact on their mental wellbeing.

'I've met the adorable Bruce a couple of times now and I'm looking forward to seeing more cuddly dogs like him supporting paramedics through the difficult times.'

At HFV we are blessed to have several close links to Ambulance Victoria through our own community members. We would like to acknowledge the amazing work our paramedics throughout Victoria do, often under very difficult and stressful circumstances, to give us the best possible health outcomes in our time of need! We thank you!



Peer support dog Callie with handler Rob Simons, Bruce with Ken Whittle and Lexie with Jo Algje



Minister for Health and Ambulance Services Jenny Mikakos (centre)



# 19th Australian Conference on HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS



**The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders will be held at the Novotel Manly, Sydney, 10-12 October 2019.**

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 plan for the future.

The conference is a great opportunity for people with a bleeding disorder and their families - parents, siblings, partners – to attend, learn more information about new treatments, gene therapy, children and young people, sport and living with a bleeding disorder etc..., make connections and become better empowered about your health.

## COMMUNITY FUNDING

To assist, HFA has allocated funding to assist community members with expenses to attend the Conference.

**HFV MEMBERS** Conference registration subsidies will be available to assist HFV member to attend the conference. Please complete your application form enclosed or contact the HFV office on 03 9555 7595 / [info@hfv.org.au](mailto:info@hfv.org.au)

Please refer to the information brochure and registration form included in this magazine, otherwise for more details and an online application form for part HFA funding go to: [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) or call HFA on 1800 807 173.

**Australian Conference,  
Sydney 10-12 October 2019**

# HEP C

*treatment update*

The Australian Government has announced that another new treatment for hepatitis C, Vosevi® (sofosbuvir with velpatasvir and voxilaprevir), has been made available on the Pharmaceutical Benefits Scheme (PBS) from 1 April 2019.

VOSEVI is listed as a re-treatment option for people who have not had success with other Direct Acting Antiviral (DAA) treatments containing a NS5A inhibitor. The treatment course is for 12 weeks.

There has been an increasing range of DAAs to treat hepatitis C available to Australians on the PBS since March 2016 and these treatments have cured nearly all people who have taken them. However, Hepatitis Australia notes that just over 3% of people who have had these DAA treatments have not been able to achieve a cure. Hepatitis clinicians hope that the introduction of Vosevi will increase success rates to 100%.

People who have had unsuccessful treatment with the existing DAAs are encouraged to go back to their doctor to discuss trying this new treatment option.

'Australia continues to be a world leader in its efforts to eliminate HCV and has the potential to be one of the first countries to reach the WHO 2030 elimination target,' said Monash University's Head of Hepatology, Professor Stuart Roberts.

HFA continues in its commitment to eliminating hepatitis C in the Australian bleeding disorders community and welcomes the announcement of this new treatment as a major step towards achieving this.



## DO YOU HAVE VON WILLEBRAND DISEASE

We are looking at ways to connect people with vWD through a new peer support group. Please contact HFV and tell us what type of peer support would work best for you ie face to face, via email, conference call and any other suggestions you may have. email: [julia@hfv.org.au](mailto:julia@hfv.org.au) or phone 03 9555 7595



Robyn & Cara (Committee Members) would like to invite ALL WOMEN WITH VWD OR OTHER BLEEDING DISORDERS to join them at the 2019 Ladies Day out (see page 8). It is wonderful opportunity to enjoy a well deserved massage, lunch together and to connect with others people with vWD.

If you are keen to connect but cannot make that date just let our staff know and we can connect you up with Robyn and Cara directly and keep you informed of other opportunities to connect.

Also, it is very important that our vWD members feel like they have a voice within our community. Having Robyn and Cara on our committee has been crucial to increasing our knowledge and understanding. Please help increase awareness by sharing your story in our magazine. Please contact [julia@hfv.org.au](mailto:julia@hfv.org.au) for any assistance.



# HFV Noticeboard

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

## In memory of John Burnham

*Sadly we lost our beloved brother John to cancer in February 2017. John lived a simple but honest life working in and for his much loved community of the Mornington Peninsula. He worked for local government for many years and contributed to many community agencies during his life always supporting those that faced more challenges than himself.*

*When our father passed away he stepped into the 'father figure' role at the tender age of 18 years supporting our mother in bringing up 6 children on her own with no car and no income other than a war pension.*



*John was my mentor, my driver, my 'go to' person in life in too many ways to mention.*

*John continued to care for our mother until her passing and put his own life on hold so we could be free to enjoy ours.*

*John worked for many years as a volunteer probationary officer taking in many disengaged young men that did not have any family supports. He mentored many throughout his life without fanfare or acknowledgement and the impact he had was obvious in his passing as so many attended the funeral to pay their respects and talk about the difference John had made in their life.*

*Generous to the end, John shared his estate across many including HFV and HFA knowing that his bequest would be used to again support those in need and to continue his spirit. I was honoured to be his Executor and his Will reflected his life. His words were few but his actions were many leading by example and not by grand standing.*



*We were all very privileged and proud to have had John as a brother and a privilege to share some of his spirit in supporting the bleeding disorder community in his passing. We miss him every day as a family and hope that through this small gesture his true belief in the goodness of others will be continued.*

Leonie Demos

HAEMOPHILIA FOUNDATION VICTORIA

## REGIONAL & OUTER METRO VISITS 2019

DO YOU HAVE A BLEEDING DISORDER?

You are invited to come and meet with HFV committee, staff and others affected by bleeding disorders.

**GEELONG**  
SUN 2ND JUNE 10AM TO 12PM  
**POSTPONED DUE TO LOW NUMBERS**

**CRANBOURNE**  
THURS 13TH JUNE 6PM - 8PM  
THE SETTLEMENT HOTEL

Food and drinks provided by HFV.

**EPPING**  
THURS 25TH JULY 6PM - 8PM  
EPPING PLAZA HOTEL

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

## ARE YOU AN EMPTY NESTER?

Has your son or daughter left home? Please send us their address so we can keep them connected with HFV!

**FREE MEMBERSHIP FOR THEIR FIRST YEAR**  
EMAIL: [info@hfv.org.au](mailto:info@hfv.org.au)  
Grandparents and extended family also invited to join!

## HAEMOPHILIA FOUNDATION VICTORIA INC

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**VICE PRESIDENT** Sharron Inglis

**TREASURER** Zev Fishman

**EXECUTIVE MEMBER** Dan Korn

### GENERAL COMMITTEE:

Karen Donaldson

Donna Field

Cara Gannon

Robyn Heal

Erika Mudie

Adam Zulawnik

**HFV is committed to Child Safety.**

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

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

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

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

Editor: Julia Broadbent

## HAEMOPHILIA TREATMENT CENTRES

### HENRY EKERT HAEMOPHILIA TREATMENT CENTRE

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

Dr Chris Barnes | Director Henry Ekert HTC  
Janine Furmedge | Clinical Nurse Consultant  
Julia Ekert | Office Data & Product Manager  
Nicola Hamilton | Physiotherapist  
Wade Wright | Social Worker

### RONALD SAWERS HAEMOPHILIA CENTRE

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

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Penny McCarthy | Clinical Nurse Consultant  
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Abi Polus | Physiotherapist  
Frankie Mullen | Physiotherapist  
Diana Harte | Psychologist  
Debra Belleli | Data Manager

2019/2020  
Membership  
Subscription  
Renewals

**DUE BY 30th JUNE**

Thanks for your support

renew online @ [www.hfv.org.au/get-involved/memberships](http://www.hfv.org.au/get-involved/memberships)



# HFV MEMBER SERVICES & PEER SUPPORT

## Membership Annual Fees:

Standard family membership

\$33.00

Concession member

\$16.50

Allied Member

\$16.50

Organisational member

\$55.00

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

## Ambulance Subscription Subsidy:

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.

(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

## To obtain an Ambulance Subsidy:

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

## Other Subsidies:

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

## Live Well Funding:

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

## Care and Counselling:

This is available through your treatment centre.

## Magazine:

Your quarterly magazine offers information and details of upcoming events.

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

The HFV Office:

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

We are located at 13 Keith Street, Hampton East, Victoria, 3188.

Phone: (03) 9555 7595

Fax: (03) 9555 7375

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

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

## MEN'S GROUP

Our current group meet for their Annual Men's Retreat – a much needed weekend away that included massages, relaxation and meditation. In 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. A 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.

WE ARE CURRENTLY LOOKING FOR A NEW CONVENOR FOR THIS GROUP. IF YOU ARE INTERESTED PLEASE CONTACT THE HFV OFFICE.

## 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.

**HAEMOPHILIA FOUNDATION VICTORIA**

# **WALK FOR BLEEDING DISORDERS AWARENESS**

**Bring your family and friends and join the  
extended HFV community for a  
LAP OF ALBERT PARK LAKE  
followed by a sausage sizzle**

**HELP SPREAD AWARENESS &  
RAISE FUNDS FOR HFV  
2.00PM SUNDAY  
20TH OCTOBER 2019**

**MORE DETAILS PLEASE GO TO [WWW.HFV.ORG.AU](http://WWW.HFV.ORG.AU)  
BOOKINGS ESSENTIAL THROUGH  
[WWW.TRYBOOKING.COM/BCQSH](http://WWW.TRYBOOKING.COM/BCQSH)**

