

# THE MISSING FACTOR

Leonard's story  
of adapting to change



What matters  
to YOU?

Rebecca shares  
her family's journey  
with haemophilia



connect • support • empower



# WINTER 2021

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Front Cover: Rebecca Handford and her family



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

## DIARY *DATES*

\* At time of print Victoria is in lock-down. All events may be cancelled, postponed or adjusted to online events where possible due to covid restrictions and/or committee recommendations. Please check our website for updates. [www.hfv.org.au](http://www.hfv.org.au)

### JUNE

30 HFV Youth Event

### JULY

3 HFV Kids Fun Morning Activity  
14 Online FOCUS GROUP session

### AUG

11 Geelong Regional Visit  
22 Wodonga (Morning) Regional Visit  
22 Benalla (Afternoon) Regional Visit

### SEPT

11 Ladies Day  
15 Cranbourne Outer Metro Visit

### OCT

8 - 9 20th Australian Conference on haemophilia, VWD & rare bleeding disorders  
10 Walk for Bleeding Disorders  
27 AGM

### NOV

19 - 21 HFV Community Camp - Lake Dewar

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

## PRESIDENT'S REPORT



As I sit to write this report we are once again in lock-down! (sigh) Hope you are well and by the time you read this it is all positive and we are all moving about freely again.

Regardless, it is a reminder of the fragility of freedoms we will continue to live in for some time now and the need to care and support each other as often as we can, when we can.

Well lock-down or not, it is cold outside and the best time of the year to enjoy our magazine curled up in your favourite chair with a hot drink and a sweet treat.

So much to share as always with another bumper issue including;

- The conversation – the relevance of HFV in a new landscape of treatments.
- Interview with Ayub with a rich life experience as the son of a refugee and wisdom beyond his 21 years of life.
- What matters to you? A thought provoking conversation to re-frame our thinking from 'what's the matter with you?' An exciting initiative from Scotland to embrace and challenge our language and thoughts.

Stories from our community continue to amaze me and remind me of the resilience many of us share and the ongoing challenges. We have several heart felt stories from our valued members and many thanks to Rebecca, Bailey and Lenny. I have had the privilege of being a small part of their

journey with haemophilia and it is with a pride I read their open stories to see how amazing they all continue to be and the milestones achieved. Very inspiring.

Again, we are thankful for our stakeholder support. 'Ask us' from Jane and Alex from the Alfred HTC is always a fabulous read with great insights. We also include interesting content around the covid-19 vaccine for people living with HIV. Please read an interview with Professor Sharon Lewin's to answer any queries and remind us of the ongoing challenges many still experience in our diverse community.

HFA conference is coming soon. We will all miss the contact of the sessions and the peer supports we once upon a time enjoyed but the important content in the sessions is still available. We encourage you all to register and support this event. HFA provide our advocacy and play such a critical role for all in our community. Please connect with the HFA team and all our allied foundations across the country to support the conference. Details are in the newsletter (page 19) and HFV are still hoping for a social aspect to tap into as well.

HFV will be asking for renewals of membership fees soon. It is critical we remain strong and can demonstrate a large and dedicated base of financial members. If you are able, please contribute to our work through your membership to show us you value

the critical and caring work of the team. We need you for our story telling as it is the sum of all our stories that bring together a united voice for advocacy and peer support. Through advocacy we now enjoy more choices than ever about treatment products and health care options. Without our foundations and the work we do as a collective, we may face a different future.

Be safe and well as we continue to live in these challenging times. Thankfully vaccines are now available and hopefully will be an option for you already or in the near future. Let us all hope that the coming months will not only bring spring flowers but a return to the post COVID life we allowed ourselves to dream about.

No matter the challenge at least you know the HFV team are here for you, keeping the information flowing and always around to connect, support and empower.

Yours in solidarity,

Leonie Demos  
HFV President

# Adapting to change



As part of the World Haemophilia Day 2021 celebrations, HFA held two excellent ZOOM sessions that looked at ways we can adapt to change. One speaker, Leonard, shared his journey with adapting to change.

Leonard is a remarkable young man who has really pushed himself and challenged himself to succeed and is working towards the freedoms independence offers.

Leonard is also a very skilled musician. He shares how he had adapted more traditional ways of learning to play the piano to ways that worked for him to foster a great talent.

Lenny states, *“Even with all the challenges, I now realise that I can still count my blessings”.*

There is science behind practising gratitude that helps us feel happier and more satisfied. So, if you are looking for some inspiration to meet your full potential or motivation to feel gratitude, please read on.

Hi, my name is Leonard, and thank you for allowing me the time to speak to you today.

I have haemophilia A at 2%, however, I am treated as severe because of other medical complications resulting from birth trauma. As a result, I have other conditions: these are hydrocephalus, ABI vision loss, mild palsy and some learning difficulties.

Hydrocephalus is caused by abnormally high pressure in the brain caused by the build-up of cerebrospinal fluid. Because of this I have a VP shunt which drains the excess spinal fluid from my brain.

The next challenge is I have a rare form of ABI vision loss known as Parinaud (or Dorsal Midbrain Syndrome). This means I can only see with one eye at a time, and I have no control over when one eye switches off and the other one

takes over. As well, both eyes have limited peripheral vision, and very limited up and down gaze. Because of the monocular vision, I have no depth perception and would trip over easily.

The other resulting challenge is mild palsy which means that one side of my body is weaker than the other, which causes issues with my balance and mobility. All the above have affected in some way my ability to learn in mainstream education.

In terms of my vision impairment, technology has played a big part in my education and my daily life. I started to become acquainted with the computer since Prep and have learnt to touch type. Learning new software also comes naturally to me. This was a real asset during the lockdown as all my classes were conducted online and we mostly

worked in isolation. In addition, I had to learn a new music software on my own to complete my music compositions in my final unit at university.

Reading music scores was fraught with difficulty due to my vision and coordination issues, however my piano teacher patiently encouraged me to read music notation.

Because of a fear of repeat shunt revisions surgery, I never felt safe doing sports, so I gravitated towards music. As a child I was fascinated, and loved hearing the beautiful melodic sounds created by my aunts and cousins on the piano. With my limited vision, I would learn each part separately, and then learn to coordinate both hands and then ditch the book and play from memory. My short term memory was severely impacted by all the neurosurgeries, but my long term

memory is fantastic.

I was surprised to discover that the due to my limited vision, my hearing is very acute, and it is perfect for music. Mum helps me enlarge the pages to A3 and often she has to increase the white space in between the staves.

As I am not involved in team sports — and classical piano is very much a solitary instrument — I picked up the clarinet and joined the school band for several years until Year 12 when I had a severe cerebral bleed which hospitalised me for 6 weeks, and as a result I had to give it up.

Recently I have completed a Bachelor of Arts with 2 majors in Music and Psychology at ACU. I chose psychology because I was intrigued to discover how my brain works and how people generally learn (even though I passed, I still don't know!) Normally a 3 year course, I completed it on a half-time basis due to my vision impairment. Even though I completed all of my assessments by the deadline it was a struggle to juggle my time between reading the textbooks, copious amounts of researching, and completing my assignments.

During the 2020 lock-down, I struggled with collaborative assignments via Zoom. My study partners thought I was being lazy and uncooperative, but I was actually just slower because it took me so long to find relevant data on the internet. It was a dark moment in my student life, but once I told them about my vision impairment they were more understanding. It improved the whole experience.

Lastly I will talk about my experience with my haemophilia. There was a time when I hated my condition. I couldn't cope with the constant injections which caused massive needle phobia. Even with all the

challenges, I now realise that I can still count my blessings. I have had excellent medical care and support both at RCH and currently at The Alfred.

Changing my treatment from factor VIII to Hemlibra has definitely been a Godsend.

When I was first told about the new regimen I was excited as I only had to do it once a week as opposed to 2 to



3 times a week which I needed for 22 years. Due to my vision impairment, I have always relied on one of my parents to do the injecting either via a port or intravenously. This new treatment is subcutaneous and has meant that I can do my own injections. To my surprise, I found that the whole procedure was more straightforward and less complicated compared to the sterile procedure for the port as there are fewer components to organise. Preparation can take place over a smaller area and it takes less time, as there is no need for complex sterile setup. With Hemlibra you only need to swab the bottle tip as well as the injection site. With intravenous injections, I was always fearful of the needle hitting a nerve. At times, the vein would hide/tissue mid-infusion and the whole procedure had to start all over again. That caused a lot of angst for me.

When I first saw the Hemlibra kit I was so surprised to discover how small the vial and syringe were, and

the little amount of product required compared to the normal factor VIII. The only challenge for me was reading the fine measurements which I managed to overcome by purchasing a cheap pair of magnifying glasses from the local chemist.

I did my first 2 treatments at the Alfred under the supervision of

the haemophilia nurses Penny and Megan. Since then, I've been successfully self infusing at home. As my confidence grows, I find that the transition has been smooth and without too many hassles. Overall, the whole experience has been positive and I think it will allow me more freedom and independence in the future.

For me, life now feels more in control because I can self-infuse instead of relying on my folks.

### **Leonard Mammoliti**

Thanks to HFA for organising this session. To watch the full zoom session, that includes health professional speakers please go to <https://rebrand.ly/nejqh6> or use the QR code below.



# THE CONVERSATION



The recent availability of the new Hemlibra treatment for people with severe haemophilia A has sparked many interesting and unexpected conversations around the HFV 'table'.

Without a doubt, this drug is life changing for many, particularly for those with inhibitors. We worked hard with HFA and others advocating for funding of this drug for our community and celebrated the success suitably.

As an organisation, we pondered what this change in treatment might mean for us and our role. Our vision for HFV is that we get to a point where we are no longer 'needed' by our community and we will be happy to hang up the hat in the knowledge that people with bleeding disorders in Victoria no longer require our advocacy or support. Hemlibra is certainly taking us a step further in this direction although of course many people in our community do not have severe haemophilia A such as those with mild or moderate haemophilia A, haemophilia B, VWD

and other rare bleeding disorders and their world doesn't change.

We certainly hope that Hemlibra will be life changing for those with severe haemophilia A, however some, as we have learned, are choosing to stay on their current regimen.

The conversations we have been part of in the community have been wide and varied with many embracing the change and others opting to stay with what they know, at least for the time being. Both the RCH and Alfred staff are very happy to speak to patients about whether Hemlibra would be a good option for them. We have found speaking to members that it can be difficult for people to process what it actually means for them and their bleeding disorder if they were to change to Hemlibra and it is a much more significant decision for them. What it does highlight is how lucky are we are, here in Australia, to have a choice in treatment product, to have options and to be able to make informed choices about our treat-

ment.

For those who have moved onto Hemlibra, they will now present as someone with mild haemophilia. From conversations over the years it is quite clear that there are still challenges of managing mild haemophilia.

Many of our members have VWD and a few have rare bleeding disorders. As our knowledge increases in the area of 'other inherited bleeding disorders' so does our understanding of the challenges many people face, particularly with lack of education of these disorders and the impact on the lives of those living with them.

Thanks to the recent extensive HFA ageing report we know there are significant challenges facing our community as we age and we are ever mindful that women still continue to have many complicated issues around their bleeding disorders. We are also aware that despite the remarkable improvements in Hep C treatment including a 'cure', long term affects



of infection for members of our community has left them with both physical, mental and financial scars and need continuing liver health checks.

As we move forward, we now hope that treatments will continue to improve for all in our bleeding disorders community. Gene therapy may play a bigger part in the near future but being genetic conditions we still need to stay strong as a community and maintain a loud voice for the journey ahead and we need **you** to be part of that conversation.

We will be running an online ZOOM Focus Group at 7.30pm on Wednesday 14th July to look at the challenges we are facing as a community and how HFV can adapt to support and advocate in the best possible ways. We will be looking at issues both metro and regionally based and really hope have regional people participate so that their issues can be addressed.

Can you spare an hour of your time to help drive **the conversations** so that we are talking about what matter to you? If so, please register your interest here or contact our office on 9555 7595.

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



## New Content



New content is added to the HFA Getting Older Info Hub regularly.

Check it out at [www.haemophilia.org.au/getting-older](http://www.haemophilia.org.au/getting-older)

### WHAT'S NEW?

- HEALTH AND WELLBEING section – lots of great info on getting older and exercise and how to manage joint replacements and other surgery
- WORK AND FINANCES section – concession cards for older people
- CONNECT TO OTHERS section – videos of personal stories

**Any feedback or ideas on more topics?**

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

## A family's challenging journey, with a **bright** future ahead

Basic human rights are inherent to us all, regardless of nationality, sex, national or ethnic origin, colour, religion, language, or any other status. They range from the most fundamental - the right to life - to those that make life worth living, such as the rights to food, education, work, health, and liberty. For many, these rights have not been upheld and force people to flee from their homes and their countries. This was the case for many of Ayub's family.

Ayub is a quietly confident young man who has haemophilia B. He has a family history that has shaped his determination and his future. He has faced challenges but is resolute in his desire to achieve and provide a safe and secure future for his family. He is articulate, considered, self-driven and humble. Ayub has kindly shared his story with us.

My name is Ayub, I am 21 years old and currently studying Economics and Finance at RMIT University and hope one day to work in investment banking. At 3 months of age I had a severe knock to my head and was hospitalised. It was at this time that I was diagnosed with severe haemophilia B. This was a huge shock to my mother as there had been no history of haemophilia in our family. At that time my mother was a refugee. She had come to Australia from Somali during the conflict and spent roughly a year and a half in a detention centre, that was far from a five star residence however gave her the support she needed.



In Somalia during that time there was great unrest, a war that is still ongoing, there had been a drought and failed governments meaning many, many Somalis were displaced seeking safety and refuge in other countries. Many fled to neighbouring countries in Africa. My father moved to the Arab Emirates with the hope to be able to work and provide for his



family. He was successful in establishing a property development business and was able to support many in his family that had been displaced. Sadly, my father became sick and passed away from cancer when I was just 6 years old.

After being housed in Maribyrnong my mother was now managing life in a new country, not speaking the language and with a baby newly diagnosed with a bleeding disorder. It must have been very challenging for her but in time other family members including her sisters from Somalia arrived in Australia and they were able to provide support for each other. Over the years we have moved to Flemington, North Melbourne and Kensington – all in close proximity to the Royal Children's Hospital to make hospital appointments more manageable. In Kensington there is an established Somali community that provides a great level of support and sense of belonging. My mother still finds English a challenge. She can understand English perfectly but it is more difficult for her to speak. It meant that I took on a significant role in our family from a young age to help my mother navigate through our world such as helping with appointments, explaining legal documents and being the main spokesperson for the family.

I feel like I missed out on having a father figure in my life and that resulted in some challenges in my youth – nothing major but enough to tilt me off course. I am glad to say that I have now found my way and I have a clear path established and high goals to aim for.

I have a younger brother who is 15. He also has haemophilia. I feel like he has had an easier journey in life as I have already paved the way and I am now a positive role model for him. He is also a great support for our mother.

Growing up with haemophilia was

not really a challenge for me, I just accepted it. I have a target joint in my right ankle that gives me a bit of trouble and have had various hospital stays over the years but nothing that I would class as 'serious'.

School was more of a challenge, not with other kids but with how I was treated by the teachers. I felt that the stigma affected me more than the condition, particularly with teachers placing me in a 'bubble'. I think because of the negative way my condition was perceived by teachers I really didn't reach out to anyone else with haemophilia but I don't feel the same anymore. I think we all have a role to help empower other individuals with bleeding disorders. We need to connect more with people who have gone through the same experiences. Whatever successes and challenges we have had in life we should share with our community, as it is empowering for all.

The future for haemophilia for me looks bright with various treatment options on the horizon. I currently treat twice a week with prophylaxis but I am having discussions around long acting factor. The only challenge for me is the prep work involved such as regular blood tests that I can't manage at the moment with my study but I think that will be the way forward for me when time allows. There is, of course, gene therapy to think about down the track but that is not something I am considering at this stage.

Looking to the future I am hoping to graduate from my Economics and Finance degree and then will consider moving to the UK where I think there is more scope for the career I wish to pursue in investment banking – of course my mother and brother would come too! We also have some family in London so



would have support and a network there.

Due to the unrest I have never been to Somalia so although I don't feel a big connection to the country itself, I do feel a strong connection to the people and the community. What I would love though is to change the western perception of Somalia. It is actually a beautiful country with a versatile geological landscape, many natural resources and with the right development and infrastructure could be much more than the third world country it is today. I hope that maybe one day, with the right education, I may be able to help influence change in Somalia for the better and for the people who live there.

Ayub

\* Ayub requested his actual photo not to be used.

## My sanctuary & our lives with haemophilia

“

My name is Rebecca. I was born in Box Hill in 1975. We lived in Ringwood and Don Valley and then when I was 16 my family moved to Waaia. I have a brother Daniel who is 42 and I had a sister Sarah who died in a car accident in 1997 and she would've been 45 now.

Growing up I knew nothing about haemophilia. I heard the stories from my mum and dad. The day my mum was in labour, dad was playing football and he got a big knock to his mouth and wouldn't stop bleeding. His head was out the car window and mum was in labour travelling to hospital and he would fill his mouth with tissues. Then, when he was about 30 his appendix ruptured and that's when he found out he had haemophilia.

My parents knew nothing about haemophilia and brushed it off as nothing too serious and they didn't understand what it was and never really looked into it with us kids. When I started my periods, I would have days off school as the bleeding was heavy and I had a lot of pain. I went through life like this until I was 22.

When I had my first child I haemorrhaged and just remember blood from my back to my feet, which I thought was normal. For weeks, I had my eyes open but couldn't see as my iron was extremely low and I was anaemic.

At this time, I still didn't know I was a carrier. I thought going to the toilet every half an hour was normal with your period, I knew no different and I was always so tired.

When my second and third children were born I waited until they were a year old to get them tested for haemophilia as that was the advice from the local doctor and they both came back negative, so I thought that we didn't have haemophilia in the family. At this stage I still had no idea what haemophilia really was or what the symptoms were.

My second and third children, Anthony and Shane, had surgery the same day. Anthony had a hernia and Shane had a haematoma in the heel from a rose thorn. Still thinking nothing of it, the doctor came out of surgery and said "wow, that was a bloody surgery". We still had no idea! Both boys came home and Anthony's scrotum was black and swollen and he was in extreme pain. We went to the local hospital and they said it was because he had worn boxer shorts and not jocks as they are more supportive and sent us home. He was screaming in pain, so we decided to go to Shepparton and all these doctors were suggesting different ideas such as draining the area or surgery and then one young doctor came in and said we should go to Melbourne. We were sent down by plane and within half a day they found out he had mild haemophilia and was treated. It stopped the bleeding and Anthony was feeling much better.

The diagnosis explained so much of them growing up. I didn't find out until Anthony was 8 and Shane 6 that they both have mild haemophilia. Anthony had ankle bleeds jumping from tractors and jumping over channels. There were big lumps on Anthony forehead like



the size of a 20 cent coin and lumps on his head that would eventually burst. He was in hospital for many days with hip bleeds still not knowing he had mild haemophilia.

My daughter, Andrea, was tested when she started her menstrual cycle and we found out her levels were 24%.

She would suffer from her periods and I remember one day she had a molar taken out and four weeks after having it removed she bled so badly for at least an hour from her mouth. It was at that time, aged 19, she went to Melbourne to find out more information. My last child Harry also has mild haemophilia, so that's 4 out of 6 of my children are affected.

The best thing after finding out the boys had haemophilia was the support from the Royal Children's Hospital as it made us understand what it is and how it's treated but the feeling of guilt and the sadness that I gave this to them still upsets me.

Anthony is now 24 and loves his football. He plays but he also knows how to protect himself but still has had many bleeds. Shane doesn't play sports and loves his fishing. When both boys were young and playing fourths, they both wore helmets and they felt so different

from everyone else and when they went to thirds Shane finished and Anthony is still playing to this day. He is very fit which has helped I think when he does have a bleed.

When Shane was young, he was at a friend's house and was bitten twice by a tiger snake. His bloods were all over the place and he needed anti venom. He was very unwell and taken to Melbourne by plane because he had haemophilia (and bitten by a snake) and it saved his life.

We were introduced to the HFV camps which was absolutely the best learning experience. Seeing more kids with haemophilia was important so my boys understood that there were kids like them, who still had a normal life. For me, it was the support of the other parents and learning about haemophilia. You never stop learning and the camps gave me the courage to give factor to my boys.

Being in the country and only knowing one other person with haemophilia in Shepparton, I felt I had to learn as much as I could when going to the local hospitals. I only see the other parents at camp once a year but it's like we reconnect where we left off at the last camp. Those families and camp mean a lot to my family and Purple Soup do a remarkable job with the kids!

Having my last child at the age of 41 I feel more relaxed with Harry but I'm a bit more protective as Harry does not understand yet what haemophilia is and want to do everything. He has started Auskick this year and he loves it. We've only had two bleeds and Harry is 5.

I would love to be more involved with the foundation but being in the country it is a bit far from Melbourne. So, my way of contributing is through my garden. What started off as a wet paddock in the winter

and a dry patch in the summer has turned into my sanctuary. We had a dam dug out and we used the dirt to make mounds of gardens. There is over 700 plants and I love quirky things in there which I get from the tip and online. My husband, Michael, and I brought a tree removal business and whilst going to different houses I loved seeing all different gardens. I had a friend visit and she said "wow, you should have an open garden"! To me, my garden is just my garden and I didn't see it as something others would be interested in but, I took her advice, and for 2 weeks we re-mulched the entire garden which was 10 truck loads of mulch and I got a few more plants.

My first open day was a huge success and I had another one about 6 weeks after we had about 120 people go through and the feedback is overwhelming.

I now open every Wednesday for the public and it's now a tourist attraction. I have people from all over Australia visiting. The feedback has been outstanding and gives me so much happiness that they enjoy it. I always have these ideas and I have visions of what I can do next. My husband, Michael, is very good with his hands making me projects out of wood.

I have colour continually throughout the year. It's clay dirt but it seems the plants like it. To water I use sprinklers and water by hand for deep soaking. I have no idea about the names of plants, I just make sure they are drought tolerant and frost hardy. My Dad was a good gardener and loved his veggie patch - that's one thing I'm not good at growing!

I have so much different art pieces and different sections in the

garden. It brings me a lot of feelings of peace and I enjoy pottering in there. There are so many butterflies, bees and birds. I have a kids section, a men's shed which is made from very old wood and iron overlooking the dam, gnomes, beach shack and I have so many sitting areas. I have set up a gold coin donation and a morning tea with scones and tea/coffee for when people visit which I donate to HFV.



I feel I now have a lot more knowledge of haemophilia and I understand what a bleed is. My boys might be a lot older now but I'm still there for them. The knowledge now, compared to my parents days, has changed a lot and the resources now are very different. There is a lot more help available now and the camps and other families have helped with the kids, and as parents we're not alone.

I look forward to camp every year. My advice to new parents is get on-board, go to the camps and watch your kids grow and make connections. We're not alone and we shouldn't feel guilt. We love our kids and they can live a normal life just like normal other kids. Don't let haemophilia hold them back.

Rebecca Handford





# COVID VACCINE 101

## for people living with HIV

Living Positive Victoria's, Vic Perrin interviewed Professor Sharon Lewin for an in-depth insight into understanding the impact of covid-19 and the vaccine for those living with HIV and other health conditions.

Whether you are living with HIV or not, this transcript of their interview provides an excellent basis for understanding how covid can affect us and how and the vaccines work.

**Professor Sharon Lewin**  
Director of the Peter Doherty Institute for Infection & Immunity

**Q: In terms of people with HIV who acquire the corona virus and the level of risk of them having severe illness or even hospitalisation, so what is the latest evidence in that?**

A: This has been a really difficult question to answer, it is because you need big studies that are well designed. Also, what we say in research, control for either factors, because we know that with covid if you do worse you are more likely to be hospitalised and are more likely to have death in people that are older, people that have co-morbidities like heart disease, kidney disease, diabetes etc and we all know that these things are more common in people with HIV. So, when you try and answer this question of what is the real added risk of HIV on top of these other risks, like age and co-morbidities, what is that number and different studies have tried it in different ways. The first few studies that were coming out of China were looking at tiny numbers, you know 4, 5 people, small case series and difficult to draw any conclusions. Then there was a big study from Cape Town, one that had much larger numbers but there were these other confounders with people living with HIV of being from lower socio-economic groups of co-morbidities. Then, a big study coming out of New York and then more recently one study from the UK and one global WHO study. I won't go into the details of all those studies because there are strengths and weaknesses to all of them but overall my take home message is that the risk of severe disease is increased for people with HIV probably about 2 times above others. The biggest risk for covid and severe disease and outcomes is age and none of us can beat that one unfortunately. Once you get over 70 and 80, so we are talking about much older, the co-morbidities

are the things that would be worrying me the most about someone sitting in front of me if they're 70 and they've got heart disease *and* kidney disease *and* diabetes *and* cancer *and* they happened to be HIV positive. It would be all those other things that put them into a higher risk group risk.

But, I think overall HIV does increase the risk of maybe two times higher, you've got the issue of 'is that someone with low CD4 counts or high CD4 counts or all CD4 counts' and there has been some association with more severe disease for people with lower CD4 counts and a greater risk of death in 1 study with low nadir CD4 if they started treatment late. So, it's not surprising people with low nadir and low current CD4 count do worse with several infections and it looks like it's the case in covid. So a long complicated answer to a long complicated question. Overall, if I could summarise, HIV probably does increase the risk of severe disease at about two-fold, not as high as the other risk factors and a low CD4 count does increase the risk of poorer outcomes.

**Q: So for older people with HIV, why is age a risk factor?**

A: It's interesting because in many infectious disease older people do worse. It is not uncommon in sepsis for example, and influenza, age is often a risk factor for just mounting a poor immune response to an infection. But the association here is striking, it goes from less than 1% mortality at less than 50 to 2 or 3% at 50-60, 4 or 5 % at 60 - 70, 10% over 70 and 20% mortality at over 80 years old, so it's a really striking relationship with age. And I think it's a combination of not just making a poor immune response to the infection but it might be a dysregulated immune response



to an infection. They are just teasing this out but it may potentially be related to your exposure to corona virus in the past and in an older person you have a greater amount of non covid corona virus interaction and that may affect the quality of your response when you actually face covid 19.

**Q: I guess the older you are you have a less robust immune system?**

A: I don't want to over complicate it but it's probably not as simple as that. It's probably that you get a slightly deregulated immune response because of your history of having been exposed to other corona viruses in the past. That is what we are beginning to learn. Interestingly, people who are older and sicker make much stronger antibody responses to covid. I think people in the community now are familiar with this idea of antibodies. We make antibodies to infections and they help clear an infection and the whole rationale for the covid vaccine is to induce antibodies. We talk about vaccines that make higher and lower antibodies but interestingly when you look at the natural history of covid people who are sicker and older have higher levels of antibodies, so it's not just how much you

make it's about the quality and the other parts of the immune system that lead to severe disease. But the relationship with age is really striking and quite different to any other infectious disease.

**Q: In terms of the difference between gender, there has been research to suggest there has been a difference between men and women in terms of the affect of having acquired corona virus, why is that?**

A: Yes, men do worse with a higher mortality rate in men. It is not fully nussed out but when your body sees a new infection, a new virus, there are different arms of the immune system that are called into action. The first is the danger signal response. The minute something lands in your body you have this innate immune system meaning that it's a very rudimentary part of evolution. Every animal has an innate response. I call it the danger signal, there is something foreign here. And then later you get the arm of the immune system that is a little bit more sophisticated, that we call the adaptive immune response. And the innate immune response involves things called interferons and other molecules and that is very sex dependent. Men and women make interferon differently and it is probably relat-

ed to how we make interferon. We know to get rid of covid, a good response to covid to clear it you need an early danger signal response making interferons and people who don't make interferons, for genetic reasons or because of sex, tend to do worse with covid. There are quite a lot of infectious diseases around, HIV for example, actually has a different immune response between men and women and for the same viral load women have a lower CD4 count and it's because of this issue of that first signal response to a virus.

**Q: What is about with co-morbidities that puts a person at higher risk of becoming sick or even hospitalised?**

A: Each of them (co-morbidity) is probably a bit different and just to make it clear that most people have mild cold like symptoms or no symptoms but there is 20% of people that will end up in hospital and of those 5% will end up in intensive care with severe disease and that all happens usually two or three weeks after initial exposure. By the time that happens there is not a lot of virus around. All your immune system is basically out of control and that leads to a lot of inflammation in the body and also some abnormal blood clotting in the lungs, in the kidneys and in the blood vessels. So something gets triggered either because of your genetics or because of your age that your immune response is not in a nice coordinated way, it is overactive. I think all those co-morbidities just add to that response and the cardiovascular ones are associated with abnormal clotting. Once that pathway gets triggered, if you have a co-morbidity it gets further amplified. They all enhance this dysregulated response that leads to severe pneumonia and involvement of the organs.

**Q: In very simple terms, how do these vaccines work?**

A: So the vaccines essentially train

your immune system to recognise a little part of covid-19 so that when your immune system is faced with the real thing, your immune system is ready to go and never allow covid-19 into any of your cells. That is pretty much the rationale for all vaccinations so you educate your immune system to recognise a piece of the virus so when the real virus comes along the immune system is ready to go immediately and stop the virus either getting into your body or stops the virus from causing disease. That is a really important distinction. Most people when they get vaccinated against say measles or hepatitis B are basically completely immune, the effective vaccines are 90% effective so you don't need to worry about it but covid 19 has 2 bits that we are protecting against. We are trying to protect against the airway getting infected and we are trying to protect against getting the severe disease and the type of immune response you need for those two things are a little bit different and I think that is what can lead to a little bit of confusion over the covid vaccines. But essentially, the vaccines deliver a piece of the virus, not the whole virus, in any of the vaccines we

are looking at, just a piece of the virus and what we call the spike protein. We've got two vaccines in Australia that are being rolled out right now. The Pfizer MRNA vaccine and the Astra Zenica Oxford Adenovirus vaccine [and they] are just two different ways to deliver that little piece of the spike protein to get your immune system working

Transcribed with permission from  
Living Positive Victoria



This article is a small part of the entire video interview. Please go to the link below or click on the QR code to view the complete video.

<https://livingpositivevictoria.org.au/covid-vaccine-101-prof-sharon-lewin/>



## HFV KIDS EVENT

Join other HFV kids for a fun morning with these great activities!

CIRCUS SKILLS  
NINJA WARRIOR

...and challenge your mum, dad or special grown-up to

MINUTE TO WIN IT

Saturday 3rd July  
9.30am - 11.30am

Mitcham

(location details will be provided when booking)

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





# WHAT MATTERS TO YOU?

What matters to you? It is an interesting and thought provoking question that I recently came across whilst reading an article about a paediatric nurse, Jennifer Rodgers, who had been named Scottish Person of the Year 2019 for 'Services to Medicine' for her work around the concept of "What Matters to You?"

This basic concept was to replace the wording around "What's the matter with you?" with "What matters to you?" for children admitted to hospital. Poster paper was provided for all children and they created a poster that was placed above their bed titled "What matters to me?" This simple idea changed the conversation from being around their health condition to provide staff with important information about the child. They could share what sports they liked or what pets they had. They might share that they don't like needles and might scream a lot or that they worry they might be forgotten about and any other information the kids chose to share.

It gave the hospital staff cues for conversations and shared hobbies or pleasures. It also provided vital information about anxieties or concerns and how to help the child manage whilst in hospital. It also offered the child comfort and empowerment to share what mattered to them.

Scotland now has a national "What matters to you?" day. With healthcare providers seeing the benefits this simple concept has brought to the experiences of patients and staff across paediatric settings the 'conversation' has moved to a national setting. The 'What matters to you?' question can be asked in many different ways such as "What are the things that are important to you at the moment?", "What are some of the things you would you like to achieve as a result of this support?" or "When you have a good day, what are the things that make it good?" These questions provide patients with the opportunity

to convey concerns such as they would like their alzheimer's medication at the same time they would normally take it at home.

How often do we ask ourselves 'what matters to me?'. In a big picture way it gives us the opportunity to evaluate our lives and whether our actions align with our values. But it is also opportunity to start a conversation with someone and give them the opportunity to reflect and be heard. This can be a valuable question we bring into all facets of our lives whether we are working in healthcare or not.

As a volunteer at an aged care facility I clearly see where this question could greatly assist people. When partnered up with an elderly lady I was told she never left her room and I was wished 'good luck' with my plans to get her out and about. It was on my first visit that with a simple question I found out why she hadn't been out of her room for years and it was because she was worried she would be left in a wheelchair in the corridor or outside and be forgotten about. After reassuring her I would not leave her on my second visit we set off for a trip around the shops, including the supermarket to her delight and to a cafe for a hot chocolate. It took one question to remove this lady from the isolation of 4 walls, to hear the birds sing, see the flowers blooming and feel the sun on her face.

Simple concepts can be so valuable, easy to implement and have such positive impact so ask yourself "What matters to me" and reach out and ask "what matters to you?"

Julia Broadbent



# Growing up with MODERATE HAEMOPHILIA A

My name is Bailey Tenace, I am 16 years old and I have moderate Haemophilia A.

For most of my younger years the only person I knew who had the same condition as me was my mum, who also has mild haemophilia A. It wasn't until we attended our first haemophilia family camp that I met other kids my own age with haemophilia.

It was a really nice feeling to be around other kids that had similar challenges to myself as a result of being born with a rare bleeding condition. I found watching the other boys self-infuse very confronting as the only time I receive factor is at the Children's Hospital and up until recently I have had a fear of needles.

Most of the boys I know have severe haemophilia and I have always admired how brave they are self-infusing factor from such a young age.

I am very grateful to have only moderate haemophilia as it means I do not need to worry about spontaneous bleeding, however, I think I am a lot more cautious in

my everyday actions than my friends with severe haemophilia as my factor VIII levels are low every day and it's a really big deal to go to the hospital whenever I get injured.

haemophilia is the community. I have made so many friends in the haemophilia community and the family camps are so much fun.

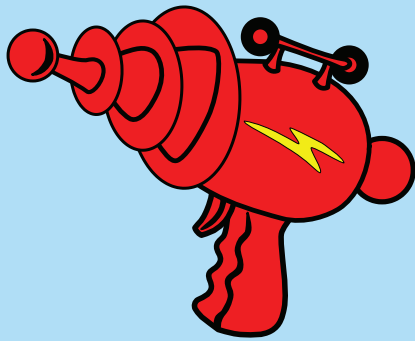
Bailey Tenace



Now that I am a teenager and I want to be more independent I have been able to overcome my fear of needles. Janine, the nurse at the Children's hospital, has now trained me up to be able to give myself medication subcutaneously by injection. This means that when I am on camp or staying at friends' houses I know I can help myself if I get injured. This has made me relax a lot more.

The best thing about having





## HFV YOUTH BOWLING & LASER TAG

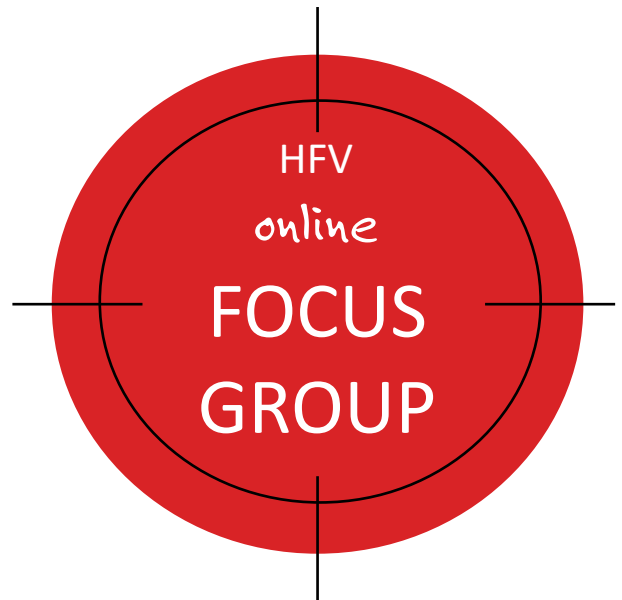
2pm - 4.30pm  
Wednesday 30th June  
(during school holidays)

**STRIKE**  
**Level 3**  
**Melbourne Central**  
**Shopping Centre**

Bookings essential by 15/6/21  
[www.trybooking.com/BRRGU](http://www.trybooking.com/BRRGU)



For ages 13+  
(Under 16 to be collected by  
parents or guardians.  
HFV staff will be in attendance)



### What Matters to you?

HFV is always looking for new ways to connect with members both metro and regionally based. We have a number of events coming up during the next few months, including regional visits, but we would like to take the opportunity to hear from members about the challenges they face and how we could improve our services to the community.

Much work has been done following our last membership engagement survey following the feedback we received.

We now have an online **FOCUS GROUP** organised, prior to our events, to ensure members can be heard and help shape the future direction of HFV. We can then attend our regional visits and events and share with the community some of the ways we will be addressing the challenges our community face.

If you would like to be involved in our online Focus Group, please either contact our office on 9555 7595 or book in through trybooking on [www.trybooking.com/BRRSU](http://www.trybooking.com/BRRSU)

**7.30pm - 8.30pm**  
**Wednesday 14th July**





HFA has released a new fact sheet, ***Sport and exercise for girls and young women with bleeding disorders.***

This was developed out of a survey of young women and their parents and answers their questions, such as:

- How can I best participate?
- What types of sport or exercise should I do?
- How can I manage my periods?
- What about injuries?
- What should I tell my coach or club?

#### Accessing the fact sheet

- Read it online or download it from Factored In - <https://tinyurl.com/FI-sport-girls>
- Ask your HTC for a copy
- Contact HFA to send you copies –  
E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or T: 1800 807 173
- Click on the QR code



HFA would like to pass on our thanks to all involved in the development: the young women and their parents and the expert health professionals for their comments and advice.





## HFV COMMUNITY CAMP 2021

Lake Dewar YMCA  
Myrniong (near Bacchus Marsh)  
19th - 21st November 2021

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



BOOKINGS  
OPEN  
SOON!

# LADIES DAY POTTERY CLASS & LUNCH



Saturday 11th September  
(date TBC) check website  
[www.hfv.org.au](http://www.hfv.org.au) for updates

Ferntree Gully  
Community  
Arts Centre





## 20<sup>TH</sup> AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

The 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders will take place this year from 8-9 October 2021 **virtually**.

We have decided to hold a virtual conference this year due to the uncertainty of the pandemic and we are very excited about the opportunities this provides. Bringing together the different parts of our community with health professionals and other stakeholders has always been stimulating and rewarding for the bleeding disorders community and other stakeholders. Without the requirement to travel so many more people will be able to participate and contribute to the discussions. We expect our virtual conference will attract more delegates than usual and create innovative learning opportunities and discussion for everyone. We are confident that nothing will be missing - in fact it will be enhanced.

### PROGRAM

We are on the road for a great program with topics across a range of areas and current issues:

- New and emerging treatments
- Managing complications of bleeding disorders
- Approaches to care in the future
- Von Willebrand disease and rarer bleeding disorders
- Living with a bleeding disorder over a lifetime
- Women and girls
- Getting Older
- Staying fit and well
- Participating in clinical trials

The program will include presentations from people living with bleeding disorders as experts, as well as specialist health professionals and others speaking on important matters that affect people living with a bleeding disorder and their families and carers. There will be plenty of opportunities ask questions and find out more.

The program will go over Friday and Saturday between 9am – 5pm. There will be keynote presentations for everyone, followed by concurrent sessions for you to choose from, and there will be breaks in between so you can plan your days. If you miss a session, you can playback later that day and all sessions will be as part of your registration for 6 months, you can log in anytime.

For up-to-date information about the conference and current program visit: [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)

### VIRTUAL POSTER DISPLAY

Posters are an integral part of the conference, and we are calling for poster abstracts for our virtual poster display. We encourage abstracts relevant to clinical practice and care, laboratory science, research, policy, living with bleeding disorders or treatment complications, peer support programs and special projects. This is a great opportunity to share ideas and experience.

See [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) for the submission form and more information. There will be prizes for the Best Abstract, and the Best Poster. Submit your abstract by Friday 30 June 2021.

### BOOKINGS NOW OPEN

<https://www.haemophilia.org.au/conferences/2021-conference/registration-1>

# ASK US

## Q AND A'S WITH ALEX & JANE - ALFRED HOSPITAL HTC TEAM

### Changing to a new treatment

In the March 2021 edition of The Missing Factor, the "Ask Us" column focused on the Covid-19 vaccine & haemophilia treatment. (To read go to [www.hfv.org.au/HFVIC/media/Images/Ask-Us-Autumn-2021.pdf](http://www.hfv.org.au/HFVIC/media/Images/Ask-Us-Autumn-2021.pdf) or scan the code below)



Further to this, we want to remind all members that when you read any medical themed articles to always personalise these to your own situation.

Please consult with your treating doctor (including your GP) and the HTC nurses when you question if this is relevant to you.

Living with haemophilia, inherited or acquired or the various bleeding disorders is complex and as we grow older, we may develop other medical conditions over time.

Again, we strongly remind members to have a GP who will work with the HTC in managing your health care.

Remember you are never alone in your health care.

Alex, Jane & The HTC Team  
Please send 'Ask Us' questions to [info@hfv.org.au](mailto:info@hfv.org.au)

*I have been on prophylaxis for many years, and now there is a new option. I know that I really struggle with change sometimes, what can I do to prepare emotionally for change over to a new treatment?*

Thanks for the great question, change can be both exciting and unsettling. Stability and routine are often at the basis of our confidence that we can manage. This will help us have a predictable and comfortable pathway through each day, but there is a risk that it may become boring. For those of you living with haemophilia, without being open to the clinical consultation at your HTC, the opportunity to discuss many of the new treatments would be missed. We do know for many people considering change, being prepared and when supplied with the clinical information can make a huge difference to how that change is experienced.

**What are the changes that are happening for the bleeding disorders community at the moment?**

- New treatments and gene therapy
- Covid protocols, such as wearing masks, using telehealth, sometimes limiting of visitors in hospital, having vaccines
- NDIS and preparation for older age under MyAgedCare

**So now it is time to ask how you can succeed when there is change going on in your life.**

- If contemplating change causes you to increase your consumption of food and other substances, review your self-care in the form of eating a balanced meal, reducing or ceasing alcohol, other substances such as cigarettes and recreational substances.
- Make sure you are getting enough exercise and enough rest.
- Spend some time doing things that you enjoy, this might be a hobby, sport, visiting with friends, significant others or making time with family
- Information, find out all that you can, have a look at any published material, read what you can, look at trustworthy websites for your information and talk with people who have some knowledge or experience in the area.
- Let your support networks know what is going on, and what support you might need, for example, would you like someone to come with you on the day that you switch over, would you like someone to learn too so that they can support you when you get home?
- Give yourself time, don't expect that you should be okay instantly.
- Check in with yourself and don't be afraid to seek help from your health care team, the varying members of the HTC, your GP, or talk with a counselor.

Alex Coombs & Jane Portnoy  
Social Workers, Haemophilia & Other Inherited Disorders Team,  
Alfred Health



## ASK US - Covid testing information

At the time of sourcing this we are half way through covid lockdown 4 and it is timely with our other piece (pg 20) on resilience and coping with change to include the following information around covid testing in this news-letter.

Please inform the tester of your bleeding disorder and always discuss with the HTC before doing so if you have any concerns.

### Information about getting tested for COVID-19

Everyone who is tested for COVID-19 helps us understand how the virus is spreading.

Follow the steps on this page to help protect yourself and others from the spread of COVID-19.

### Step-by-step advice

1. If you feel unwell, stay home and check your symptoms. Do not go to work or school.
2. Get tested, even if you have the mildest symptoms of COVID-19.
3. Find a nearby COVID-19 testing site.
4. You can use the Testing registration form to fill in a form online before your COVID-19 test. This is optional.
5. Get tested then go straight home and isolate while you wait for your results. Do not go to work or out shopping, stay at home.
6. If you live with others, there is information available on what to do.
7. If you are worried about losing income while you wait for your test results, or you need to take time off work if you test positive for COVID-19, financial and other support is available.
8. You should receive your results within two days. If you have not received a result after five days and you were tested at:
  - a clinic, hospital or pathology collection centre, call the place where you were tested
  - a pop-up site, call the provider for the site where you were tested
  - a drive-through testing site, call the Onsite Doctor Results Hotline on 03 8669 0255, from Monday to Friday between 8am and 7pm, or on weekends between 9am to 5pm.
9. If you were not tested at any of the above locations or you have been unable to obtain your results, call the Coronavirus Test Results Hotline on 1800 573 222, from Monday to Friday between 8am and 6pm.
10. If you test negative, your doctor or the clinic where you were tested will tell you your result. Once you feel well go about your normal activity, following the restrictions for your location.
11. If you continue to have symptoms, ring your general practitioner for advice. If you become very unwell and are having trouble breathing contact triple zero (000).

Alex Coombs & Jane Portnoy

Social Workers, Haemophilia & Other Inherited Disorders Team,  
Alfred Health

Source: Dept of Health & Human Services Victoria

[https://urldefense.com/v3/\\_\\_https://www.dhhs.vic.gov.au/getting-tested\\_\\_;!!NDYExDT0u85SdT4!53tJJheT2V1F5V0fnpYPpmG\\_cFtt87D9GcAVazBcutR-CRIgOjFqxqUEuYoaBS9YD\\_g\\$](https://urldefense.com/v3/__https://www.dhhs.vic.gov.au/getting-tested__;!!NDYExDT0u85SdT4!53tJJheT2V1F5V0fnpYPpmG_cFtt87D9GcAVazBcutR-CRIgOjFqxqUEuYoaBS9YD_g$)

## HFV Membership Subscriptions 2021 -2022

You will be receiving your annual membership subscription renewal notice (by mail) shortly.

**Subscriptions are due by 30th June 2021.**

You can also access a form online at <https://rebrand.ly/3g0iq3j>

Please complete and email to [info@hfv.org.au](mailto:info@hfv.org.au)



**Thanks for your support!**



Patient Portal

Dear Members of the bleeding disorder community of Victoria,

### Alfred Health Patient Portal

Today we want make you aware of a recent development in access to some of your patient records. To access the patient portal you will need to individually register (if there is more than one of you who is an Alfred patient in the household i.e. husband, wife, adult siblings etc)

Your patient portal account will allow you to:

- View your upcoming appointments
- View your pathology results from tests conducted at the Alfred Health pathology laboratory (14 days after a final result has been determined), excluding anatomical pathology and genetic testing
- View letters that have been sent to you and/or external providers
- View your inpatient discharge summaries from any unit
- Receive secure messages from your healthcare team.

Please follow the link below:

<https://www.alfredhealth.org.au/patients-families-friends/patient-portal>

We hope this will give you a bit more sense of access and control of your individual records. A handy aspect of the portal is to easily check on your appointments to avoid a missed appointment!

As always this information is protected by the Alfred IT security system, so please do not give out your registration details to others and keep these private and not in easily obvious places.

Take care

Alex & Jane

Social Workers

Ronald Sawers Haemophilia Treatment Centre

# WALK FOR BLEEDING DISORDERS AWARENESS 10 OCT 2021

HELPING TO SPREAD AWARENESS &  
RAISE FUNDS FOR HEV

save  
the  
date

Location to be  
confirmed



**HAEMOPHILIA FOUNDATION VICTORIA INC**

13 Keith Street

Hampton East VIC 3195

Phone: 03 9555 7595

Mon - Thurs 8.30am - 4.30pm

\* Due to the NBN we can no longer offer a fax service

info@hfv.org.au

www.hfv.org.au

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Claire Brunet

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P. (03) 9345 5099 E. he.htc@rch.org.auDr 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 Treatment Centre**The Alfred, 1st Floor, William Buckland Centre  
Commercial Road, Melbourne 3004  
P. (03) 9076 2178 E. (03) haemophilia@alfred.org.auProfessor Huyen Tran | Director of RSHC  
Penny McCarthy | Clinical Nurse Consultant  
Megan Walsh | Clinical Nurse Consultant  
Kara Cordiner | Haemophilia Nurse Consultant  
Susan Findlay | Secretary  
Alex Coombs | Haemophilia Social Worker  
Jane Portnoy | Hepatitis C & Haemophilia Social Worker  
Abi Polus | Physiotherapist  
Frankie Mullen | Physiotherapist  
Catherine Haley | Physiotherapist  
Diana Harte | Psychologist  
Debra Belleli | Data Manager**Membership Annual Fees:**

\$33.00 Standard family membership

\$16.50 Concession / Allied (Youth Free)

\$55.00 Organisational member

\* 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.

**MedicAlerts**

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.

**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 2021 ten 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 each alternate year get to enjoy an event with a twist. They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant. In 2021 we will be offering a pottery class and lunch!

**YOUTH GROUP**

The Youth Group will be meeting up mid-year in 2021 to participate in a laser skirmish and bowling activity. 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**

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

**KIDS EVENTS**

We have opportunities for kids to connect throughout the year. In 2021 we will be offering a fun morning session mid-year that include circus skills, ninja warrior and minute to win it. This is an inclusive morning games session for kids with bleeding disorder, their sibling and their parents can join in too!



HAEMOPHILIA FOUNDATION VICTORIA

# REGIONAL VISITS ROAD TRIP 2021

WE ARE COMING TO YOU

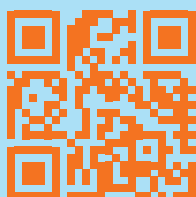
**GEE LONG - 6.30pm Wed 11th August**

**WODONGA - 10.00 am Sun 22nd August**

**BENALLA - 2.00pm Sun 22nd August**

**CRANBOURNE - 6.30pm Wed 15th Sept**

For more information about  
times and locations and  
to make a booking go to  
[www.trybooking.com/BRQGI](http://www.trybooking.com/BRQGI)



All events are  
subject to changes  
in accordance with  
Covid-19 restrictions.  
Please check our web-  
site for updates  
[www.hfv.org.au](http://www.hfv.org.au)



ONLINE  
FOCUS GROUP...

7.30- 8.30pm 14th July  
We need your help!

Prior to our regional visits HFV is conducting an online FOCUS GROUP via ZOOM to help us understand the challenges currently faced by all our members including our regional, rural and metro members. This session will provide the opportunity to voice your concerns and work through some ways HFV can address these issues. It will also help us to identify regional areas to visit as part of our Regional Visits Program.  
[www.trybooking.com/BRRSU](http://www.trybooking.com/BRRSU)

