

THE MISSING FACTOR

**COVID-19 vaccine &
bleeding disorders**
FREQUENTLY ASKED QUESTIONS

*Enjoying a family
day together*



connect • support • empower

SPRING 2021

- 03 President's report
- 04 COVID-19 vaccine & bleeding disorders
- 06 Resilience & adapting to change: career, work & sport
- 08 To tattoo...or not to tattoo
- 10 HFV men's retreat
- 11 HFV family day
- 12 20th Australian (Virtual) Conference: Great reasons to attend
- 13 HEP can't wait
- 14 Keep connected - through YOUR local council
- 15 Youth matters: HFV youth event
- 16 Ask us: Mental health & accessing the NDIS
- 18 Thank you & farewell from Julia
- 19 Online focus group
- 20 Outpatient prescription charges at Alfred Health



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

DIARY DATES

* All events may be cancelled, postponed or adjusted to online events where possible due to potential covid restrictions and/or committee recommendations. Please check our website for updates. www.hfv.org.au

SEPT

- 11 ~~Ladies Day~~ **Cancelled**
- 15 ~~Cranbourne Outer Metro Visit~~ **Cancelled**

OCT

- 8 - 9 20th Australian Conference on haemophilia, VWD & rare bleeding disorders
- 10 - 16 Walk for Bleeding Disorders
- 27 AGM

NOV

- 19 - 21 ~~HFV Community Camp~~ **Postponed**

Date TBC Online Community Trivia Night 2021

2022

MAY

- 13 - 15 HFV Community Camp

HFV is committed to Child Safety.
Our Child Safety Statement is available for review on our website 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

Welcome to another bumper newsletter and something fabulous to read as we yet again navigate life in lockdown. We sincerely hope everyone is doing as best you can and getting support if you need it. Always remember the teams at HFV, HFA and our HTC's are always here to offer any supports we can especially if the challenges of life are compounded by your bleeding disorder or of those you love and care for. As these challenges continue to drag on it is more important than ever to drop the 'brave face' and reach out as I think we are all in need of some extra TLC...I know I am.

As always, I encourage you to enjoy the fabulous diversity on offer in the newsletter. Something for everyone, I am sure, from covid vaccines, to tattoos and reflections on our HFV men's weekend, youth event and family morning!

WE NEED YOUR HELP! HFA have produced a Hepatitis C based infographic postcard, that is included in with this edition of The Missing Factor, targeting two specific groups of people of concern. The first group who are at risk for hep C are those who received blood product or a plasma-derived clotting factor concentrate before 1993. The second group is those that have been 'cured' of Hep C but has their liver recovered? The idea of the postcard is to make you think - Is this me? Is this my uncle? Is this my mother? Is this my friend? Please consider getting the conversation started around whether this could be a health issue for any of your family or friends. Consider using the postcard as a conversation starter. It is so important that these people get treatment if needed or the correct follow-up if they have cirrhosis or extensive liver scarring.

Sadly, but probably not that surprising the family camp for 2021 is again postponed. As we live in such times of uncertainty, we are hesitant to bring our community together and create any additional risks to the health and wellbeing of those we support. However, we are planning some exciting alternative events to try to connect with you all so stay tuned. In the meantime, we thank you for your support of our decisions. I am sure we are all feeling the added disappointment of the continual cancellations of the things we look forward to. However, let's keep the positivity alive and think how much fun we will all have when we get to gather again and celebrate life as a community (and ignore each other's covid kilos we are accumulating).

There is some sadness as I promote this edition as it is the last newsletter that will be created by Julia Broadbent. Julia has decided after 15 years of dedicated service to HFV it is time to take on other frontiers. Julia has been a critical member of the HFV team, and her leaving will create an enormous gap for us to fill. In the time Julia has been working with us we have witnessed two royal weddings, survived Donald Trump presidency, welcomed so many new treatments for our community, watched as Hep C has almost been eradicated and HFV has had many presidents and committee members come and go and always one of the things of consistency has been the positive energy of Julia in her role. Children have been born into the haemophilia community and are now in secondary school and many families will not have known HFV without Julia's amazing inputs.

I am sure you will all join me to thank Julia for her many



years of dedication to our community. We thank her for her positive energy, her 'can do' attitude and her ability to always welcome everyone to our community with sincerity and kindness. We thank Julia for the countless editions of the newsletter she has magically created from many threads of diverse sources of information and collated into a newsletter bursting with so many articles where we have shared people's stories and learnt so much more about how to survive our complex lives living with a bleeding disorder.

We all thank Julia so much for all she has brought to our work and the countless ways she has enriched our lives. We wish her all the very best for whatever exciting direction her career may take, and we look forward to enjoying her success to come. Julia will leave a big gap for us to try to fill however it is time for her to share her enormous skill set with others. With a full heart of gratitude, we thank you Julia for all you have achieved for our community. We wish you well and wait with excitement to see what amazing things your future will bring.

Be safe to everyone and take care of each other until next time.

Leonie Demos
HFV President

COVID-19 vaccine & bleeding disorders

FREQUENTLY ASKED QUESTIONS

With the rollout of the COVID-19 vaccine commencing in Australia, members of the community have asked us about how this will impact on people with bleeding disorders.

The Australian Haemophilia Centre Directors' Organisation (AHCDO) has endorsed the joint COVID-19 vaccination guidance for people with bleeding disorders, produced by the World Federation of Hemophilia (WFH), European Association for Haemophilia and Allied Disorders (EAHAD), European Haemophilia Consortium (EHC), and U.S. National Hemophilia Foundation (NHF).

This has detailed information and is available on the AHCDO website (see NEWS) – www.ahcdo.org.au AHCDO has advised HFA on some answers to some common questions.



Photo by Artem Podrez from Pexels

Q1 – Is the COVID-19 vaccination safe for people with bleeding disorders?

A - In general the COVID-19 vaccine is as safe and effective for people with bleeding disorders as for anybody else without a bleeding disorder. As with all immunisations, there are some steps you may need to take before being vaccinated. See Qs 4,5 and 6 below.

The Australian Government has a careful and thorough process to check that the COVID-19 vaccines in Australia are safe and effective before it makes them available to the community. You can find more information about this on HealthDirect, the Australian Government-funded health information website- www.healthdirect.gov.au/coronavirus

Q2 – Am I in a priority population because of my bleeding disorder?

A - People with bleeding disorders are not at greater risk of contracting COVID-19 or developing a severe form of the disease, so they are not considered a priority group for vaccination.

The Australian Government will roll out the vaccine in phases, starting with priority populations. Some groups have been prioritised because they will be the most affected if they become infected with COVID19. Information on the phases for the vaccine rollout is on the HealthDirect website - www.healthdirect.gov.au/covid-19-vaccination

Q3 – Where will I receive my vaccination?

A - You can find more information about where you can get the vaccine on the HealthDirect website - www.healthdirect.gov.au/covid-19-vaccination

Q4 – Do I need treatment for my bleeding disorder before I have the vaccine?

A - Both of the currently approved vaccines require 2 intramuscular injections over a number of weeks for full vaccination. They cannot be given sub-cutaneously (under the skin) like the Fluvax.

You may also need to have treatment beforehand to prevent bleeding from the injection. Please contact your HTC to discuss this. If you have a moderate or severe bleeding disorder, such as haemophilia or VWD or a rare clotting factor deficiency:

- If you are on prophylaxis with clotting factor concentrate, time it to have it on the day of your vaccination before the injection
- If you do not routinely give yourself factor, please contact your HTC for advice.
- If you are taking emicizumab (Hemlibra®), whether you have inhibitors or not, just follow your usual treatment plan - you do not need to take any extra treatments before the vaccine injection.

If you have mild haemophilia or Type 1 or Type 2 VWD:

- Usually you will not need any special treatment with factor concen-

trate or DDAVP before the vaccine. Please follow the general precautions for immunisations - see below.

- However, if you have ever had a problem with bleeding from an injection in the past, please contact your HTC or haematologist for advice before you have the vaccine.

Q5 – How do I prevent bleeding with the vaccine injection?

A – As you would do with any immunisation, let the health care provider who is giving the vaccine know that you have a bleeding disorder.

- Ask them to use the smallest gauge needle that is available for the vaccine. Some COVID-19 vaccines must be administered with the needle and syringe package provided and a smaller gauge needle may not be possible.
- Apply pressure on the injection site for 10 minutes after the injection to reduce bleeding and swelling.
- Check the injection site several minutes and 2-4 hours after the injection, both visually and by touching it, to make sure bleeding and swelling (haematoma) has not occurred.
- You may have discomfort in the arm for 1-2 days afterwards. If it becomes worse and there is swelling, contact your Haemophilia Treatment Centre (HTC).
- Do not lift anything heavy with that arm for 24 hours, eg, shopping bags, gym weights, handbags.

Q6 – Does my bleeding disorder mean I am more likely to have an allergic reaction?

A - No.

It is rare, but some of the vaccines are known to cause allergic reactions in people who have a history of severe allergic reaction.

If you have ever had an allergic reaction to any vaccine or drug (for example, a severe allergic reaction to PEG or other vaccines) or have had other severe allergic reactions, you should talk to your doctor before you have the vaccine.

If you experience an allergic reaction after the vaccine injection (fever, warmth, redness, itchy skin, rash, shortness of breath, or swelling of the face or tongue), contact your doctor immediately and go to the nearest hospital emergency department straight away as it can be life-threatening.

Q7 – Do I need to have the Fluvax as well as the COVID-19 vaccine?

A - Current advice is that people should still have a Fluvax this season as well as the COVID vaccination.

Ask your doctor about having Fluvax and the timing of having it if you are also having the COVID vaccination.

If you have any questions about your bleeding disorder in relation to the COVID-19 vaccine, contact your Haemophilia Treatment Centre or your treating haematologist. Contact details for Haemophilia Treatment Centres are available on the HFA website - www.haemophilia.org.au/support-services/treatment-services

Important Note: This information was developed by Haemophilia Foundation Australia for education and information purposes only and does not replace advice from a treating health professional. Always see your health care provider for assessment and advice about your individual health before taking action or relying on published information.

These FAQs may be updated as more information becomes known.

<https://www.haemophilia.org.au/publications/news/covid-19-vaccine-faqs-updated>

(The Alfred HTC team recommend printing out a copy of this fact sheet and taking it with you when you get vaccinated. Question 5 - How do I prevent bleeding with the vaccine injection is of particular importance).



Resilience & adapting to change: career, work & sport

To celebrate World Haemophilia Day HFA held a ZOOM session discussing 'Resilience & adapting to change'.

Speakers included:
Penny McCarthy -
Haemophilia Clinical Nurse at
The Alfred Hospital

Hayley Coulson -
Physiotherapist at Lady
Cilento Children's Hospital

Nicoletta Crollini -
Social Worker at Royal Prince
Alfred Hospital

Darren Crouch -
Alfred Haemophilia Patient

Darren, a local Melbournian, was really happy to share his journey with haemophilia, his career and his life experiences along the way. Darren's easy going nature and can-do attitude is endearing. Darren also highlights the benefits of a good relationship with his HTC team.

We've shared a transcript of his talk with you here.



It's a pleasure to be a part of this and I am happy about change. I am 29 and going on 30. I am dreading that time mid-year turning the big 3-0. I am one of two boys and I am less than 1%. It was a bit of a shock to the family when I was diagnosed. Have I let it stop me? Definitely not. I am a fully qualified mechanic working in the heavy diesel industry for over 10 years now. I worked two jobs when I was younger, I've travelled overseas all through Vietnam and Thailand as well with my medication, which is massive and taking that much product overseas has its challenges, but Penny has touched on the support the HTC's offer and it's huge. Communication is key and the HTC team don't want to be dealing with mum or dad, they want to be dealing with you and your partner and who you choose to be with and look to be with for the rest of your life.

You are 100% in control with whatever you want to do

within reason. I rode a motor-bike everyday for two or three years up and down the Monash freeway in Melbourne. As much to Penny's disgust it was not a problem, I snowboarded all through Winter as well. There are multiple things I have done so just don't let it hold you back. But how you support that and articulate yourself and move forward with that is all on yourself. There have been multiple points raised tonight about the appropriate PPE (personal protective equipment) and safety gear. Make sure you are not snowboarding down Mount Buller with no helmet on. I water skied with mum and dad when I was younger, and mum and dad made sure I had my helmet on. I had all the appropriate things, it's just like really, really channel those outlets that you have. And the support from your family is huge. My girlfriend is probably one of my biggest supporters now and still mum and dad are my supporters but I'm in control of it.

Your employer is huge, just be open with them, that's just the best advice I can have. My employer is probably one of the most supportive companies I have ever seen. Just be open with them, like the old myth that you're going to get a cut and bleed out on them and die in the lunch room, it's not a thing but the awareness is not there, the education of haemophilia and severe haemophilia is not out there. You know your diabetes, cancers, epilepsy that is all so commonly known these days but haemophilia being so rare it's just the support or the education for the employer is not that known. So, the big thing there is just be open about it, don't hide it, it's nothing to be ashamed of.

I live a normal life, absolutely, 100% a normal life. I have done multiple trials through the Alfred and there has been some really good ones come out of it and I'm on one now and it's a fantastic trial. I did their extended half-life trial originally which was perfect that was really, really good so there are some really good things that can come out of it.

Penny touched on when you transition over it's a big scary world, it's not that scary. Just be open, just be yourself. The MyABDR app is one of the perfect things for record keeping. If you can log onto Facebook for an hour a day you can spend 2 minutes putting your diary into your phone recording [treatment]. I was terrible at it and Penny was forever on the phone and that soon changes because you learn from those simple things, it's communication and if Penny isn't ringing you, damn sure it's Megan, so God bless their cotton socks, I tell you!

So the other thing is friends and family. Really focus on that. Don't let your friends get you down about it. If your friends are saying you're never going to work, you're

never going to get a job, get new friends and really find the people that push positivity and support you. Don't be scared of change, just look at how you can target it, how you can overcome it is a big thing.

I've done multiple things. I've worked in field service, worked remotely and big major events in Melbourne but again just knowing that your treatment is key, if your HTC give you a treatment plan just stick to it. You will be at predominantly normal levels according to that medication that you are on and just don't be silly. If you fall over, make sure you medicate yourself. It is really just key simple things.

A lot of people ask about tattoos. I am covered in tattoos. I have multiple, I've got my arm done, my chest done, my legs are all done. You can do it, just make sure you notify your tattooist, it's not a problem. You can live a normal life, just be cautious and aware of how you do it. Consult your HTC nurses prior to getting tattoos. They will tell you they are against them, but you should because you need to make sure you are maintaining the right clotting factor levels and you don't want to be doing your treatment just to be getting a tattoo. That is not what it is there for. Don't be dosing yourself and having your factor just to go out and get a tattoo.

My mum has aged very well with the normal 'boy' things that you do. The punch ons and arguments with my brother that we use to have in the Crouch household was fantastic. Boys will be boys. How do you control what they do? If they want to have a kick of the footy and have a swollen foot for 3 days, it's going to happen, that the joy of having boys with haemophilia.

However, my parents supported

me very well. They had a lot to learn. My mum learnt how to medicate me through the vein and do all my medication from home, so she supported me by learning about it, asking the appropriate questions and letting me do things and making sure I have the appropriate safety. She didn't wrap me up in cotton wool, don't wrap your boy with haemophilia up and shelter him from the world, it's not required. Let him get out there and experience things but make sure his treatment plan is up to date and be medicating him accordingly and make sure you communicate with your HTC. If he hits his head hard well take him into hospital obviously. The biggest thing is not to hold them back but support them otherwise they are going to get to 18 and be scared of change and not want to do anything.

Printed with permission from HFA and Darren Crouch

To view the complete Zoom Session and hear from all the speakers including Penny McCarthy, Hayley Coulson, Nicoletta Crollini please go to <https://www.haemophilia.org.au/publications/webinars/adapting-to-change-world-haemophilia-day-2021>



TO TATTOO... OR NOT TO TATTOO

As Darren highlighted in the previous article, as with any cohort, people with bleeding disorders do get tattoos.

Here we share Better Health Channel's article on tattoos including complications, health regulations and procedures.

We also explore some of the reasons people from our community choose to get tattoos and their experiences.

Before we start, **what is the advice and recommendations of our adult HTC team around getting tattoos?**

We asked Penny McCarthy Alfred HTC Clinical Nurse. Penny shared, "our 'company line' on tattoos is that we do not condone tattoos, however, if you are going to have them, please get them done on the day of your prophylaxis if you are someone that treats at home. If you have mild haemophilia, you should be fine (without additional treatment). If you are unsure you can always check with your HTC team".



If you are considering getting a tattoo, it is important to have a good think about it before going ahead. Always choose a tattooist whose business is registered with their local council to minimise the risks of complications.

Getting a tattoo can change your body image for life. Some things to consider include:

- Tattoos are permanent. It may be the look you want now, but how will you feel about it when you are older?
- Tattooing can be a painful process. Depending on the complexity and size of the design, it can also take quite a while (days or weeks) to complete.
- Tattoos can be expensive— the costs will vary depending on the size, design, number of colours used and the time taken.
- How will your family and friends feel about your tattoo and how will it affect your relationships?
- Having a visible tattoo may be an issue for particular workplaces and could affect your employment opportunities.
- Unwanted tattoos can cause psychological problems, especially if they are easily visible.

If you decide to get a tattoo and it is your first, it may be helpful to get a small design. A small design will be easier to complete, and is a less extreme 'trial piece' for determining whether you like having a permanent tattoo. It is important that you carefully consider the reasons for getting a tattoo, and the way it may impact on your life, before going through with it.

Complications of tattooing

Choosing a registered, experienced tattooist can help reduce the risk of complications. However, getting a tattoo can still put you at risk of:

- infections, such blood-borne viruses
- allergic reactions
- thick scars

If the tattoo extends over a mole, it may make it more difficult to identify any changes in colour or size or any other changes that occur to the mole. While a tattoo will not increase the chance of a mole becoming cancerous, it is important to be aware that a tattoo may obscure any changes that might occur.

Another possible reaction is that you may become distressed after the procedure, due to regret at getting the tattoo. This has been identified as one of the major problems involved with tattoos.

Choosing a tattooist

Choose an experienced tattooist whose business is registered with their local council. A certificate of registration should be made available for you to see. Make sure the tattoo premises you choose looks clean and professional.

Check that the tattooist uses single-use and sterile equipment for each client, or thoroughly cleans and disinfects their equipment before use, by putting it through a steriliser. If a premises looks dodgy, trust your judgement and keep away.

Don't be afraid to ask questions about the tattooist's experience and procedures. If they do not answer your questions, or you are not satisfied or comfortable with them, do not feel pressured – take your business elsewhere.

To comply with health regulations:

- The premises must be kept clean and hygienic.
- Instruments and needles must be sterile at the time of use.
- The operator should not have exposed cuts or wounds, and their clothes must be clean.
- The proprietor or operator must provide you with health information before any procedure is done.

After a tattooing procedure

After tattooing your body, the operator should:

- wash your skin with warm water and soap, and single use wipes
- remove their gloves, wash and pat dry their hands, then re-glove using new gloves
- apply antiseptic cream from a single-use container to the treated area of skin and cover the site with a sterile dressing.

Avoiding infection after getting a tattoo

As a tattoo is an open wound, it is important that you take precautions to help avoid the chance of infection, including:

- Follow the advice given by the tattooist regarding after-care and how best to prevent infection.
- Make sure your skin is free from cuts, abrasions or infection at the proposed site of the tattoo. If you have a skin infection, you should only have a tattoo performed once the infection is completely healed and the skin has returned to normal.
- Two to three hours after being tattooed, wash the area with soap and pat dry with a clean towel.
- After washing, using new gloves, lightly apply some ointment to the area that has been provided or recommended by the tattooist or a health professional, such as a pharmacist. Repeat this process as necessary when you feel the skin is drying out.
- Do not touch the tattooed skin area and do not pick at any scabs that may form.
- Avoid wearing tight or dirty clothing, or exposing the tattoo to direct sunlight.
- Avoid soaking your tattoo in water such as in a bath, swimming pool or the sea.

If the tattooed area becomes very red, swollen or tender to touch, it may be infected. An infected tattoo can be treated with antibiotics.

Consult your doctor immediately and notify the tattooist if:

- your skin becomes very irritated, itchy, red or sore
- the site doesn't heal
- you experience pain or swelling
- there is continual bleeding or discharge from the site
- you have any other concerns about the procedure.

<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/tattoos>

Community and committee members Robyn and Cara have VWD and share their experiences.

"We both have tattoos, we took our medication the day before we got our tattoos and for three days after. We have four tattoos in total and we found our tattoos all healed really well.

We had bepanten cream for three days and then changed to paw paw cream for two weeks.

We did bleed a bit while being tattooed, but that can also depend on the work and the tattoo artist. If they are a bit heavy handed and go a bit deep or if you have a lot of shading, it could bleed a bit.

Just check with your HTC team if you have any concerns".

Men's Retreat



"You are warmly welcome
to join us for the next one!"

In May this year, on a perfect autumn weekend, I had the pleasure of attending HFV's men's retreat again. Nine of us descended upon the farm known as 'Lochinver' near Maryborough for a weekend of relaxing and reconnecting. After the year that was in 2020, without being able to connect in person, it was great to be together again. We had two years of life and medical misadventure to catch up on. And weren't we lucky to squeeze it in, before more restrictions and lockdowns caused 2021 to also go pear-shaped.

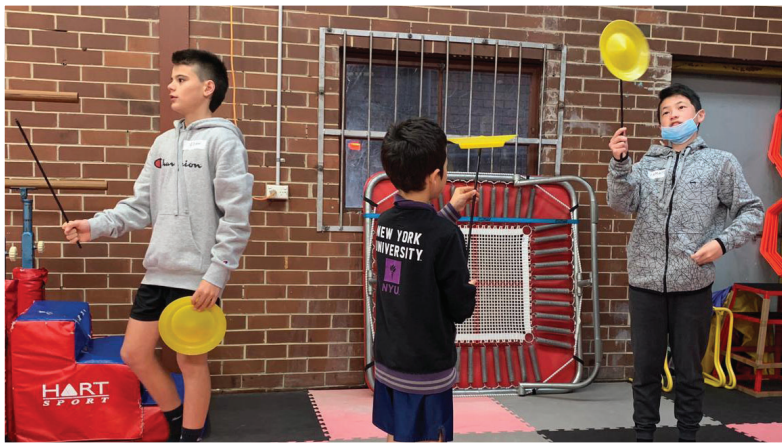
We made up a reasonably diverse group, even from a haemophilia point of view. Representatives from the A and B tribes; different shades of severe, moderate, and mild; inhibitors here, a virus or two there; and a wide variety of able bodiedness. Also among our number were a mix of guys boldly embracing the new treatments, like gene therapy and extended half-life therapies. Our youngest was in his 30s and we had several gentlemen over 60. We didn't venture into public, but it's amusing to imagine what a stranger would make of us as a group, with our wide variety of gaits and limps, wheelchairs and walking aids. With a couple of prosthetic legs between us, the average number of legs was less than two per person.

What we lacked in nimble sure footedness and physical stamina, we made up for in an ability to self deprecate. As usual, some colourful characters took it upon themselves to entertain the rest of us. Finding new and interesting ways to laugh at each other and ourselves kept us remarkably amused. We had fun reminiscing about long gone eras of treatment and outdated models of care, and in more poignant moments, medical practitioners who had made a difference to us, and who we remember with great fondness and gratitude. By retelling some favourite stories, we kept alive the memory of some departed fellows and friends.

We were blessed to be looked after yet again by an exceptionally kind and gifted therapist. Everything Sharon does is healing, whether it is cook and serve food, gently massage our damaged joints, or speak kindly and anticipate needs. Sharon has become an integral part of our retreats and we all come away feeling extra refreshed thanks to her. Sharon, we hope you can continue to join us.

A massive heartfelt thank you to the wonderful people at Haemophilia Foundation Victoria, for funding the retreat and creating such a pleasurable opportunity for us to spend quality time with haemophilia peers. HFV is steadfastly committed to our retreat, but we should never assume that our foundation will forever be in a position to support it so generously with precious funding. If you are reading this and you haven't joined us before, please don't wait another year. You are warmly welcome to join us for the next one.

Anthony McCarthy - HFV Member



HFV Family Day

After so much uncertainty during the last 18 months we were delighted to be able to go ahead with our HFV Family Day. With lockdowns on either side of the event we really were very lucky to forge ahead as planned.

We hear our community when they say they'd like more opportunities to connect with each other throughout the year. For the children it is important to have the opportunity to rekindle relationships with other kids with similar experiences and really develop those friendships that they have made at camp through shared experiences. To see these children together and very comfortable in each others presence is very special.

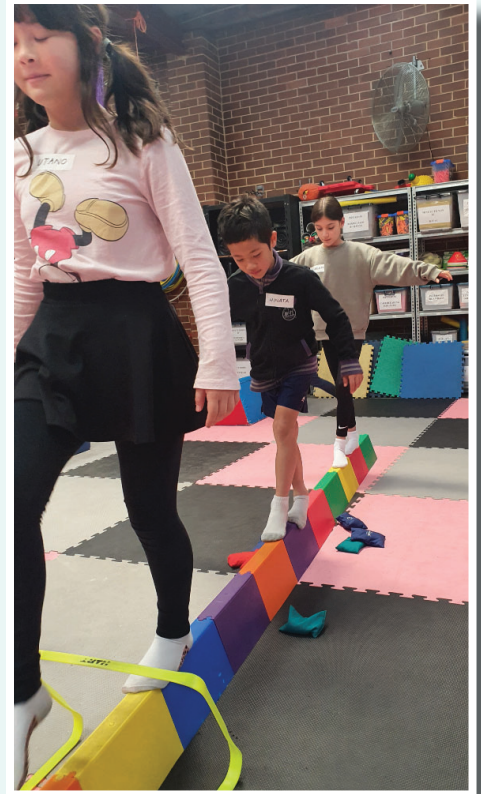
We headed to a great little venue called Fitnessworx in Mitcham. Drew facilitated a great session including circus skills and ninja warrior training! Drew did an amazing job of not only accommodating a wide range of ages but made it super fun, really inclusive and also challenging.

The kids were focused and persistent and all achieved success with their circus skills. A few of the adults couldn't resist the temptation to join in... and of course it always looks easier than it actually is!

We ended with some great results and a couple of kids even completed the whole ninja warrior challenge but **all** kids had a great time challenging themselves!

It was a really lovely morning and a great opportunity for our families, both kids and parents, to re-connect.

Covid has certainly made it more difficult for us to connect face to face but we will continue to offer opportunities for social interaction for our members, both face to face and online, as we navigate this covid world we are living in - together!



20TH AUSTRALIAN CONFERENCE

ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

Why are you attending the virtual conference this year?

With the National Conference being held online as a virtual conference it makes it much more accessible to everyone. If you have never been able to attend a conference before due to travel challenges, work or family commitments this is an opportunity you should embrace.

As HFA and the conference committee work hard behind the scenes we can be assured that the range of topics on offer will be relevant to us all.

At previous conferences there were always 3 concurrent sessions. This conference will have just two concurrent sessions, meaning there will be less opportunity to miss out. A huge benefit of this conference is that all sessions will be recorded so if you have registered your attendance you will be able to access all the recorded sessions after the conference. The beauty of this is that if there are two concurrent sessions that interest you, you'll not miss out! If you cannot attend a live session due to work commitments or childcare needs you can watch at a later date or time. The benefits of being able to log into the live sessions is that you will be able to interact, ask questions and really be involved.

As much as we have all adapted to the online space, please don't underestimate the amount of work behind the scenes that has already gone into providing this conference for our community. To ensure we continue to be able to access conferences like this in the future we need your support in attending.

The bleeding disorders community is unique and the conference really highlights this uniqueness with the drawing together of health professionals alongside community members. It is a union that brings together an array of benefits to both the community and our healthcare providers.

Show your support by REGISTERING NOW. Registration is \$50 per person. If this fee is a barrier to you registering, please just email andrea@hfv.org.au and Andrea will assist you (confidentially). We do not want any members to miss out on the opportunity to attend and benefit from all on offer.



"Being virtual, I can attend at my own convenience, multi-task around work/family commitments yet get brilliant insights into new treatments, research and hearing other people's stories in the community - all for the price of a family takeaway dinner!" - Bernard

"It will be great to attend the online conference because I want to hear the latest updates on new treatments and gene therapies, it is easy to listen to the recorded sessions during my own time". - Claire

www.haemophilia.org.au/conferences/2021





HEP CAN'T WAIT!

WORLD HEPATITIS DAY 2021

World Hepatitis Day is marked globally on 28 July. In 2021 we joined the global community in the message of Hep can't wait!, reminding us that we need to be proactive and act on viral hepatitis.

Hepatitis C has had a profound effect on our community. In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of blood borne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

WHAT ARE THE KEY ISSUES IN 2021?

Revolutionary new hep C treatments are now available in Australia. They are easy to take – tablets not injections - with very high cure rates and few side effects.

Who is at risk?

If you had a blood product or a plasma-derived clotting factor concentrate before 1993, you could be at risk for hepatitis C.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some might not

even know they have hep C. This could be the case for some women and men with mild bleeding disorders who may have had very few treatments in their lifetime and never thought of themselves as at risk for hep C. If this is you, don't wait to be tested – find out if you have hep C. Treatment is simple and hep C can be cured.

You have been cured – has your liver recovered?

If you don't know the answer to that question, don't wait to find out. Take the time to **contact your hepatitis specialist and check your liver test results.**

It's very important to check that you don't need ongoing follow-up with a liver specialist. For example, if you have cirrhosis or extensive scarring and have successful treatment, you will still need ongoing care of your liver.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research is continuing into new and improved hep C treatments and management of advanced liver disease.

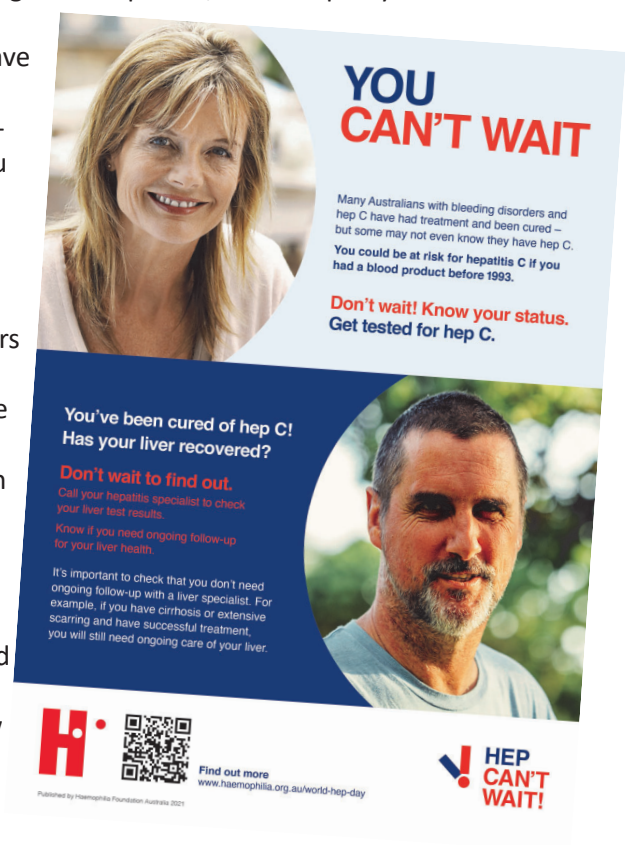
PERSONAL STORIES

We thank Gavin Finkelstein, HFA President, and Mary Jane for sharing their personal stories about living with hep C, treatment and being cured. Read their stories on the HFA website (see below).

FOR MORE INFORMATION

Visit

- www.world.hepatitisday.org.au
- The HFA World Hepatitis Day page – www.haemophilia.org.au/world-hep-day



YOU CAN'T WAIT

Many Australians with bleeding disorders and hep C have had treatment and been cured – but some may not even know they have hep C. You could be at risk for hepatitis C if you had a blood product before 1993.

Don't wait! Know your status. Get tested for hep C.

You've been cured of hep C! Has your liver recovered?

Don't wait to find out. Call your hepatitis specialist to check your liver test results. Know if you need ongoing follow-up for your liver health.

It's important to check that you don't need ongoing follow-up with a liver specialist. For example, if you have cirrhosis or extensive scarring and have successful treatment, you will still need ongoing care of your liver.

H Find out more www.haemophilia.org.au/world-hep-day

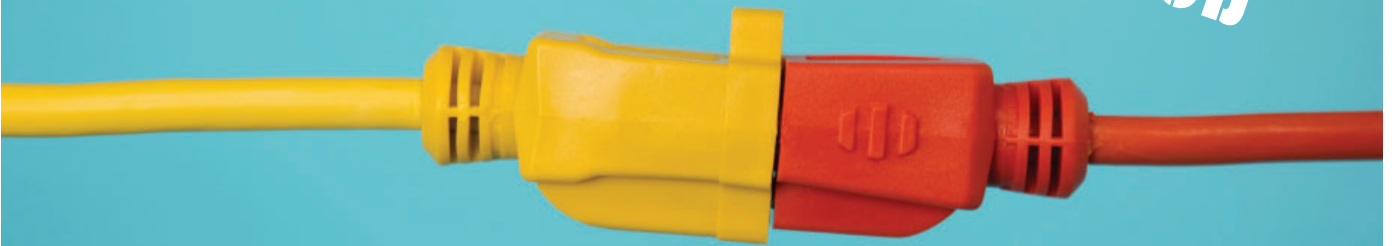
Published by Haemophilia Foundation Australia 2021

HEP CAN'T WAIT!

KEEP CONNECTED

through YOUR local council

LEGO
Club



During these current challenging times with covid, snap lockdowns, and general uncertainty we have all had to make adjustments to our lives.

When we are free to move about more freely many of us are still staying close to home, supporting our local cafes and restaurants and making the most of what's on our doorsteps. Many of our local councils also offer a wide range of social engagement opportunities, many of which are free and provide excellent ways for us to build our support networks and connection within our own local communities.

BREWERS
CLUB

So what kind of programs are on offer through your local council?

Here are some of the programs we've found but it would be well worth checking out your local council website to see if there is something on offer for you or a family member or friend. Social connectedness is so important for our mental health, so when we see opportunities to connect we

should embrace them.

There are lots of programs that we are all quite familiar with such as exercises classes including pilates (Abi Polus - Alfred HTC physio highly recommend pilates for everyone! You can always speak to the Alfred physio team before commencing any exercise classes and Abi is more than happy to talk to any personal trainers or exercise professional about programs that would suit your individual needs). There are also various art based classes on offer through your local councils.

Here are a few more unusual opportunities on offer and ways to connect with your local community!

Kingston Council offer Brain Training at various locations.

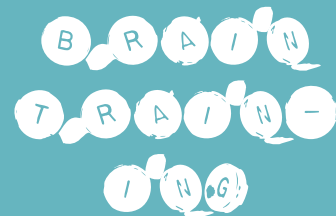
Want to learn new skills and have a laugh with a like-minded adult group? Give your brain a workout with activities such as quizzes, memory puzzles and word search.

East Gippsland Shire Council offer LEGO Club! Junior LEGO enthusiasts are invited to attend after-school LEGO Club sessions held at various library locations across the shire. The sessions incorporate

freestyle creativity and construction activities with themes.

Bayside Council has The Bayside Brewers Club

which offers a friendly social setting to learn about brewing. Members have a wide range of experience in many aspects of brewing including beer, cider and mead, which they will gladly share with others.



These are just a few examples of what is on offer. Check out your local council website and find ways to connect. For many, taking that first step to joining something new can be challenging and pushes us outside our comfort zone but the rewards make it worth it and these activities can offer some positivity in our lives.



There was a great turn out of for our HFV YOUTH EVENT at Melbourne Central in June! We were lucky to manage to go ahead with the event given it ended up being sandwiched between lockdown 4 and 5.

A great group of youth attended and it was a real privilege to see these young people get together and enjoy each others company, with a bit of competitive bowling and some pool to top it off!

Over the last decade and more I have had the pleasure to have been able to see these kids at camp, community picnics and other events. I've been able to get to know them and it's a real privilege to watch them grow up into the outstanding young people I saw that day.

In order to join us, Caitlyn took a regional train on her own, for the first time, all the way to Melbourne. It was a great achievement and certainly helped build her confidence and independence. Ben Inglis is now teaching Grade 1's full time and took time out of his much needed school holiday to reconnect with our youth. Ben is such a great role model and when I think of community I often think of Ben. The safe place camp and the commu-

nity have provided for Ben has meant he continues to give back, and continues to be rewarded.

To see our youth, that not so long ago were little kids running around at camp or just a couple of years ago self infusing for the first time in front of an audience, now growing up into the young people they have

es of mentorship at camp that these youth have experienced themselves.

A big thanks to Chris Phong for organising this event and for keeping the youth perspective and voice prioritised and ever present as a valued member on committee.



become is so rewarding. These young people are all polite, engaging and were more than happy to have a meaningful conversation with me. As I depart from my role at HFV my hope for these young people is that they continue their connection with each other, continue to engage with HFV and become mentors to younger kids within our community so that younger kids can have the wonderful experienc-



ASK US

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

Mental Health Care

MENTAL HEALTH CARE

Q: I am struggling with depression and anxiety at present. How can I get any help with the costs of seeing a counsellor for this?

A: Arrange a long appointment with a General Practitioners (GP's) and let them know that you want to talk about a mental health care plan. You may need to complete a questionnaire and/or discuss the issues that you are experiencing. If they consider these issues to be consistent with the criteria the GP is able to make a mental health care plan which would entitle you to a Medicare rebate for 6 sessions, if it is going well but you need further sessions your GP can review the plan and extend it for a further 4 more sessions. At the moment there are an additional 10 sessions available due to increases in the funding because of the impact of COVID. Usually the local GP's are best placed to make a referral as they will know the counsellors in your area.

Under this program you are entitled to see a mental health clinician who is a provider with Medicare. You can see a Mental Health Social Worker, a Psychologist, another allied health practitioner, if they are a Medicare provider.

TIPS

- If the chemistry is not right, then this may not be the best counsellor for you. Talk to the counsellor or your GP. You are able to use the remaining sessions of your plan with another counsellor.
- If you are a young person aged between 12-25 and need information relating to general mental health, physical health, work and study and alcohol and other drugs, Headspace may be a good and low cost option.
- Use your local HTC as a resource, we can provide short term counselling, personalised advice and referrals, and help assess what would be best for you.
- Your GP is able to make the mental health plan and referral to a counsellor
- Under a mental health plan you will receive a rebate from Medicare, but many agencies are able to provide counselling to low income and health care card holders at a lower rate.
- You may find your local Community Health Centre has counsellors, and fees are assessed depending on your income.

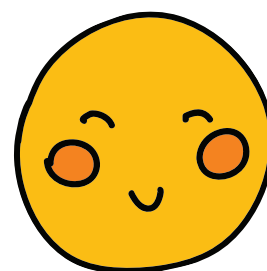
- There are some great online counselling options, including Beyond Blue.

USEFUL LINKS

<https://headspace.org.au/headspace-centres/>

<https://www.beyondblue.org.au/>

<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/mental-health-care-plans>





ASK US

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

Accessing the NDIS

ACCESSING THE NDIS

Q: I'm interested in applying to the NDIS that I've heard about and wonder what sort of things can I apply for?

A: It is important to have an understanding of the National Disability Insurance Scheme (NDIS) and National Disability Insurance Authority (NDIA).

- The NDIA is the agency that administers the NDIS.
- The NDIS is a scheme that provide funding for your need for services, support and equipment/modifications to the home/car etc. which will enable you to be as independent as possible.

Having haemophilia as a medical condition in itself will not qualify you for the NDIS as it is about the impairments associated with haemophilia that impact on your day to day functioning, and capacity to be independent.

This must be impressed upon in your Access Request form.

- You need to identify your goals and needs.
- Have a physiotherapist/occupational therapist/medical officer assessment to support your request.

To get started:

- Go to the NDIS online to obtain an 'Access Request form' either to be downloaded or sent out.
- Complete this form in consultation with your GP initially and/or your specialist team.
- As an applicant you must be under 65 years of age.
- If you are successful in accessing the NDIS you currently retain this for life.

USEFUL LINKS

NDIS:

<https://www.ndis.gov.au/applying-access-ndis/am-i-eligible> Ph 1800 800 110

<https://www.ndis.gov.au/how-apply-ndis/what-access-request-form#supporting-evidence-form>

Disability Gateway:

The Disability Gateway has information and services to help people with disability, their family, friends and carers, to find the support they need in Australia.

Ph: 1800 643 787 Monday to Friday, 8am to 8pm AEST

https://www.disabilitygateway.gov.au/?gclid=CjwKCAjwuvvmH-BhAxEiwAWAYj-D7HMYbjd9x-VaPna7JUXShEbv6tidJ3Cx0QPY-i60JMSB6I6EXIzTiRoCmUcQA-vD_BwE&gclid=aw.ds



THANK YOU and farewell



After more than 15 years as the Communications Coordinator at HFV I have decided it is time to move on. I'd like to take this opportunity to thank you all for the tremendous support I have been given throughout my time here. Considering my family are not personally affected by bleeding disorders, I am so humbled to have been welcomed into this unique community as one of your own.

It has been a privilege to get to know so many of you and your families over the years. In my role, you have been so generous in sharing your personal stories with me and the community and I will be forever grateful for the opportunity to hear those histories. Each story I have heard, so personal to the individual but familiar to so many in this community, has woven itself into the fabric of our existence. HFV is the sum of you all and your lived experiences and it has been a true honour to have been in this position to share this unified voice of the community.

I sincerely feel that this community is unique and that HFV is worth preserving. As the treatments improve and life experience for those with bleeding disorders excel we must always remember what has got us to this point. I have a photo on my desk of some young men from HFV in the 1990s. They were attending a HFV event for those living with HIV. I am not sure if any of these young men survived. I do not know their names. I do know they had parents, brothers and sisters, families and friends that loved them dearly. I look at that photo regularly. For me, this photo represented all the families that have lost someone due to their bleeding disorder. Many lives have been lost and there are many loved ones still very much missed today. To the families who have lost someone, I'd like you to know that

they *and you* are ever present in our minds and our work.

From my many years with HFV there are traits that stand out in this community. I am sure the challenges of living with a bleeding disorder provide both empathy and strength of character but a stand out attribute for this community is without doubt resilience.

During my time I have had the pleasure of working with five Presidents...Ann, James, Neil, Michelle and Leonie! You all managed this often challenging role in your own unique way, supporting staff, enhancing and evolving HFV to what we have today. Thank you, sincerely, to each and every one of you. You have all supported me in so many ways.

Leonie has been at the helm for the last 6 years and her incredible leadership skills, strategy and direction has meant it has been a great pleasure working and learning from Leonie. I am very thankful of the mentorship and friendship offered by Leonie. I know I leave HFV in her very capable hands with the great support of Dan as Vice-President and all our committee.

There have been many committee and sub-committee members to cross over the threshold of 13 Keith Street during my time, all of whom have brought passion, commitment and dedication to the shared goal of a united voice for HFV. To all of you, thank you for the support you have given me, for the hours spent around the committee table, for the many friendships that have developed along the way and for being such a good humoured bunch!

Thanks to the staff at HFA for providing support and guidance, the HTC

teams for being open to working with me and HFV to provide the best outcomes from their patients. For members I have had the pleasure of spending time with at camps, Christmas picnics and peer support events, thank you for sharing a small piece of your lives with me.

Finally, to Andrea and Pamela...my two amazing colleagues over my decade and a half. I couldn't have asked for better people to spend my days with. I feel so lucky that these two colleagues became my friends and made me laugh every single day!

Andrea, you always go above and beyond. All decisions you make fundamentally come down to what is the best decision for the community regardless of whether it is the harder option. You are such an asset to HFV and I am very glad I had the opportunity to work with you for so long. We have certainly been an exceptional team, bound together by a shared sense of humour. Our long lasting friendship will certainly continue beyond the realms of HFV but I do look forward to hearing updates on our dog walks together!

So I leave this unique organisation forever grateful that I had the opportunities to cross paths, share journeys and make memories with so many of you and to be able to call many of you a friend. I wish you and your families all the very best for the future. HFV is just the sum of its people, which is why I leave with a strong sense of pride, gratitude and hope that HFV continues to provide peer support for generations to come.

Julia

ANNUAL GENERAL MEETING**2021**

This year our AGM will be an online ZOOM event and we are delighted to announce that we will have special guest speakers joining us for a Q and A!

**Professor Huyen Tran
& Dr Chris Barnes**

Wednesday October 27th @ 7pm

Booking are essential through
www.trybooking.com/BRRGL

Please watch out for more information in your inbox regarding the AGM closer to the time...or book in now!

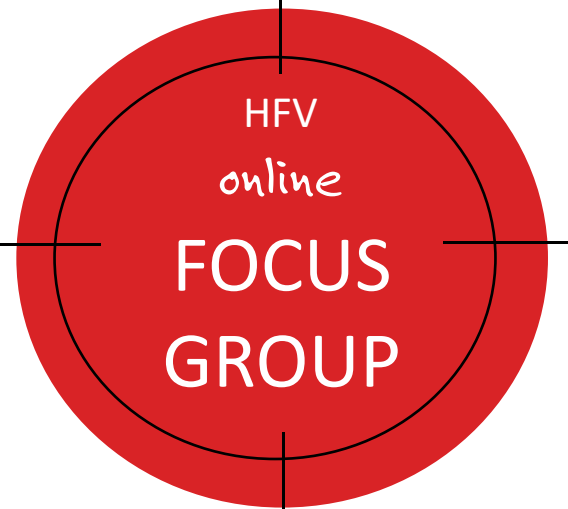
**BABY NEWS!**

After the last year and a half we are all looking for some good news to celebrate and we are delighted to announce the arrival of baby Tèo.

Claire is an important member of our committee and many of you will know Claire, Ben and Louie from HFV camps.

What a gorgeous photo and such a happy big brother!

Congratulation to the Brunet-Coney family on the safe arrival of Tèo from the HFV community!



We recently held an online community focus group to help us as an organisation understand where our community is feeling gaps or how we can improve our services. The discussions and feedback we received was invaluable.

We have a diverse committee including people with haemophilia, VWD and parents that help form our understanding of the needs of the community but the more representation and input we have the better and it is only if we hear your voice that we can act.

We would like to thank all those who registered for the very first HFV on-line member forum. For those who attended the session, we appreciated the frank and open discussion and we welcomed your various suggestions. We hope you found it as worthwhile as our committee and staff did.

Staff have collated and prioritised a number of draft action points from the session to be tabled at the next committee meeting. The action points are in 4 broad areas; communication, support services, events, and advocacy.

For those who were unable to make it to the forum on the night, please do not hesitate to touch base, especially if you have any issues or thoughts to share with HFV. Simply email andrea@hfv.org.au or phone the office 03 9555 7595 if you would like to chat. (If the office is unattended when you phone, please leave your name and number so that we can get back in touch).

The valuable feedback and conversations generated from this session has meant we will continue to offer focus group sessions in the future, later this year or early next year, to maintain our connection and relevance to our community.

Andrea McColl
Executive Assistant

Outpatient Prescription Medication Charges

Your Services

Alfred Health
Pharmacy Services

Payment Information



55 Commercial Rd.
Melbourne VIC 3004
T (03) 9076 2000

www.alfredhealth.org.au

Further information:

If you would like to provide feedback or request a copy of this information in a different format, contact us at patient.info@alfred.org.au, or direct pharmacy queries to pharmadmin@alfred.org.au, Ph. 03 9076 2061

Do I have to pay for my medication?

When you receive your medications from the Outpatient Pharmacy; directly or through the post; you will need to pay for your medications and any postage costs. Payment will need to be made at the time of collection or before posting.

How much do I have to pay for my medication?

The cost of PBS medication is set by the Australian Government each year.

General PBS Payments		Concession/Pension PBS Payments	
Number of medicines	Total cost	Number of medicines	Total cost
1	(up to) \$41.30	1	\$6.60
2	(up to) \$82.60	2	\$13.20
3	(up to) \$123.90	3	\$19.80
Up to \$41.30 per item		Up to \$6.60 per item	

For each **non PBS medication**, the charge is up to \$41.30 for general patients or \$6.60 for concession or pension card holders for each month of medication supplied.

If you prefer to have your medication posted to you, there will be additional postage costs. These will vary based on the number of items we need to post: a large parcel is \$30, and a small parcel is \$18. Please talk to the pharmacist for more information.

I am taking a lot of medications: is there any reduction in how much I have to pay?

You may be eligible for a Medicare Safety Net Card depending on how many prescriptions you get each calendar year. Please talk to the pharmacist for more information.

How do I pay for my medications?

Please bring a suitable payment method when you come to the hospital.

You can pay by credit card, credit-debit card or BPAY online at the time you collect your medication. Cash payments can be made at Australia Post (located opposite Outpatients Pharmacy) prior to collection.

If you are arranging a supply of medication over the phone, please have your credit or credit/debit card with you when you call.

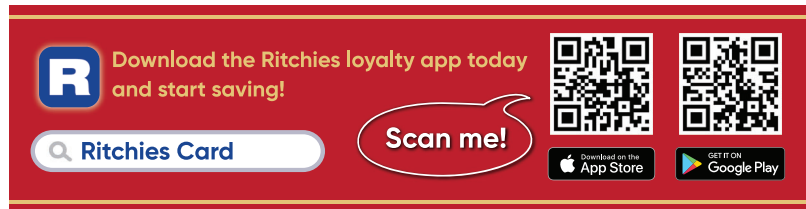
What if I can't pay on the day?

If you have no method of payment with you, you will need to let the pharmacist know when you first arrive at the pharmacy.

If you are worried or unable to pay for your medication please let your doctor and pharmacist know. You can also speak to the Alfred Health Accounts Team to arrange a payment. They can be reached on phone 9076 3147.

I have other questions about my payments, who can I talk to?

If you need to speak with someone regarding your account please call Alfred Health Accounts Team on 9076 3147.



R Download the Ritchies loyalty app today and start saving!

Scan me!

Ritchies Card

Download on the App Store

GET IT ON Google Play

An easy way to support HFV!

Our fundraising partner Ritchies IGA, are launching their new Ritchies Card, incorporating the Community Benefit Program and this will not only benefit our organisation, but also all our members.

The program now has an App for both IOS and Android smart devices. For those members who don't have a smart phone, or would like a physical card, this option is also available and can be linked to the App.

Every month, our organisation will receive 0.5%* of our members' spend in Ritchies Stores PLUS our members will receive special offers and member only specials via the App.

Featuring monthly promotions, cheaper prices for you, Collect and Win, as well as games and lots more fun things to do, this is a great opportunity to support HFV.

You can download the Apps by scanning the QR codes above - or search for Ritchies in the Apple App Store or Google Play.

*T&C's apply see <https://www.ritchies.com.au/ritchiescardterms>

THANK YOU

Following another year of uncertainty with the impact of covid and many people struggling with the financial impact this has caused we would just like to take a moment to say a very big thank you to everyone who has made a donation to HFV or has renewed their membership. Big or small, your donation makes a huge difference to the programs and support we can offer our members.

As well as donations received from members we would like to acknowledge the staff at **Melbourne Pathology** for selecting HFV as one of the charities they supported this year with their generous donation!



**HFV
COMMUNITY
CAMP**

NEW DATE FOR 2022

**Lake Dewar YMCA
Myrniong (near Bacchus Marsh)
13th - 15th May 2022**

**DATE
CHANGED
to 2022!**

Unfortunately, due to covid and uncertainly the committee have made the difficult decision to postpone this camp until 2022 to ensure we can provide a safe setting.

The good news is we all have something to look forward to next year!

HFV Membership Subscriptions 2021 -2022

Thank you to all those members that have renewed their membership but it's not too late!
Subscriptions were due by 30th June 2021.

If you haven't yet renewed you can access a fillable form online at <https://rebrand.ly/3g0iq3j>

Please complete and email
to: info@hfv.org.au



Thank you for your support!

Please SHARE YOUR STORY

With a new Communications Officer starting at HFV soon we encourage you all to share your story! It will be a great way to not only introduce yourself but to help them to understand our community, including our history.



It is always challenging starting in a new role but the added burden of covid means working from home and limited face to face member contact. This adds to the difficulty of representing our community in the HFV magazine. So if you have ever considered sharing your story, or an 'update' if you have shared in the past, please consider doing so now. It will be a great way to support our new employee and HFV. We can do phone/zoom interviews or send you questions to answer over email...whatever works for you!

Please contact info@hfv.org.au
Thank you.

Call for nominations for HFV LIFE MEMBERSHIP

We are currently calling for nominations for Life Membership to HFV. This is to recognise those from within our community that have made an outstanding contribution over many years.

Please find an enclosed Life Membership nomination form to be returned to the HFV office for consideration.



REDCLASSIC
Supporting the Bleeding Disorders Community

WALK FOR BLEEDING DISORDER AWARENESS CHALLENGE

10-16 OCT 2021

Are you up to the challenge? This year we may not be able to walk together as group but we can still be unified in our goal of increasing awareness for bleeding disorders!

Join us and other community members from around **VICTORIA AND AUSTRALIA** in walking, riding, running, hopping, skipping or jumping around your local area and let's see how many kilometres we can clock up during **Bleeding Disorders Awareness Week!!!**

Remember, this is a National Challenge so let's show the other states what Victorians are made of!

SIMPLE RULES...

- walk, run or ride (hop, skip or jump!)
- within the government restrictions
- all participants kms are counted
- you can wear red (optional)
- you can dress up (optional)
- share photos on HFA social media (optional)
- remember to tally your kilometres
- share your suburb to be mapped nationally!
- most importantly...HAVE FUN!

To register please go to

www.haemophilia.org.au/BDAWRC

HFV is offering TWO \$50 prizes!

- 1 x \$50 visa gift card - Randomly selected
- 1 X \$50 visa gift card - Best **awareness** photo



**Bleeding Disorders
AWARENESS WEEK**

10-16 OCTOBER 2021



HAEMOPHILIA FOUNDATION VICTORIA INC

13 Keith Street
Hampton East VIC 3188
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

PATRON: Dr Alison Street AO

EXECUTIVE ASSISTANT

Andrea McColl andrea@hfv.org.au

COMMUNICATIONS COORDINATOR

Julia Broadbent julia@hfv.org.au

COMMITTEE OF MANAGEMENT:

PRESIDENT Leonie Demos

VICE PRESIDENT Dan Korn

TREASURER Bernard Paes

EXECUTIVE MEMBER Donna Field

GENERAL COMMITTEE:

Cara Gannon

Robyn Heal

Claire Brunet

Chris Phong

Zev Fishman



Henry Ekert

Haemophilia Treatment Centre

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

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Julia Ekert | Office Data & Product Manager
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.au

Professor 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!



20TH 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:

- Managing bleeds
- Treating and diagnosing VWD
- Specific issues for women and girls
- Bleeding disorders and young people
- Understanding and managing pain
- Getting older
- Living with hepatitis C/HIV
- Mental health
- Managing change
- Optimising peer support

Discover up-to-date information with speakers from around the world, including:

- David Stephenson, Haemophilia Physiotherapist from the UK
- Professor David Lillicrap from the Department of Pathology and Molecular Medicine at Queen's University, Kingston, Canada
- Professor Mike Makris, Honorary Consultant Haematologist at Sheffield Teaching Hospitals NHS Trust, UK
- Paul McLaughlin, from the UK and current chairman of the Haemophilia Chartered Physiotherapists Association (HCPA)
- Dr Christian Barton, who works in both research and private practice treating sports and musculoskeletal patients in Melbourne.

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 to 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



BOOKINGS NOW OPEN

www.haemophilia.org.au/conferences/2021-conference/registration-1



Achieving the extraordinary together