

WINTER 2023



THE MISSING FACTOR

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

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: Yarrow Ruane

PRESIDENT'S REPORT

A final word from me...

Hi to all at HFV

It is with mixed feelings that I write this President report. After 8 years in the privileged role as President I am stepping out and welcoming Dan Korn as the new person to the chair.

The past years have been an honour and with many highlights to take with me in my memory box and too many to mention. Twinning with Myanmar, HFV ball and all the glamour of the spectacular event, conferences and celebrations of milestones along the way.

But by far my greatest memories are all around the time I have spent with all in our community. Our community is a rich tapestry of individuals, families, health professionals and all that dedicate themselves to surviving and thriving life with an inherited bleeding disorder.

My sincere thanks to all - the committee throughout the years, all who have contributed to so many achievements for HFV and most importantly the staff - Julia, Yarrow and Andrea. Working in a tiny workplace with limited resources, less salary than you deserve and so many 'out of hours' expected and yet never a complaint and never anything but positive energy and the 'what can we do' attitude that is so greatly appreciated especially by me.

HFV is in great hands. I

will continue on the executive as we try to recruit more members but I hand the leadership to Dan and know he will do great things as HFV move into yet another era... From me I say thank you with a heart full of gratitude for the privilege of being in the role of President for HFV.



Leonie Demos

HFV President



A changing of the HFV guards

Today we say a big congratulations to the new HFV president Dan Korn and the vice president Donna Field, and a huge thankyou to our outgoing president Leonie Demos. Who could believe it has already been eight years since Leonie first stepped into the presidential shoes? So much has changed for the bleeding disorders community since 2015 and Leonie has been a steadfast leader through it all. Here at HFV, we want to congratulate Leonie for her tireless efforts in advocating for Victorians with a bleeding disorder and their loved ones. It has not been an easy road and Leonie has taken every unexpected challenge on the chin. Here are some of our favourite memories of Leonie's presidency.





Leonie's first ever president's report from February 2015!

Achieving the extraordinary together

A word from *our* president, Leonie Demos

Committee of Management

President

Leonie Demos

Vice President

Sharron Inglis

Treasurer

Zev Fishman

Executive Member

Ann Roberts

General Committee

Matthew Blogg

Karen Donaldson

Carol Ebert

Donna Field

Jodie Caris

A new year at HFV and a new journey begins

A happy new year to all in our community on behalf of the Committee of Management. As we start 2015 we also start the 61st year at HFV after our AGM in November and a newly elected committee.

I would like to start my new journey as President to acknowledge the hard work of many that goes behind the scenes at HFV all year. After many hours of volunteer support the Committee has farewelled two of our members as Michelle and Damian take a very well earned break. Both have contributed in many ways especially Michelle as a previous President. Michelle's dedication to HFV has value added in so many ways. From stakeholder engagement at a National level and also at a very personal level for many families as she has offered her shoulder many times to support others in difficult times. Both Michelle and Damian have left a significant 'footprint' at HFV that the current committee will continue to 'walk in' and we wish them well with their break and thank them most sincerely. We look forward to both of them continuing their support to our community in a different capacity as they take a different path beyond their role as members on the Committee.

Ann Roberts, our former President, has very kindly agreed to remain on the Executive and her very many years of experience will be valued by all, especially me, as I lead for the first time in very big footsteps from my predecessors as President.

Sharron has stepped up as Vice President to support our Executive and Zev has very kindly agreed to continue to monitor our finances as Treasurer. Fortunately others on the committee have stayed and we are all very committed and keen to take on all the challenges 2015 will bring.

There are many exciting projects on the horizon at HFV and we hope you will join in to support us as we build a stronger community for the future. In an ever changing landscape of reduced funding and changes at both Federal and State level in the health and allied sector HFV need to be united and strong as we work with our partners at HFA, other state associations, our treatment centres and other agencies beyond.

HFV are very blessed to have dedicated staff with both Julia and Andrea that always go above and beyond their role to provide the best possible service to our community. Like the COM, Julia and Andrea are dedicated in their time as they plan and develop programs and camps to enrich and support our community.

However HFV isn't just a name on a banner or the letterhead of this newsletter. HFV isn't just our staff, the COM and a handful of volunteers. HFV is you, your family and your community. As President, I invite you to be part of this journey and walk alongside us. Contact me, or any of the COM or our very welcoming staff for a chat and tell us what you want HFV to be. We are waiting to listen....

Looking forward to continuing our journey together and hope to see you next time at one of upcoming exciting events!

"So be sure when we step, Step with care and great tact. And remember that life's A Great Balancing Act. And will we succeed? Yes! We will, indeed! (98 and ¾ percent guaranteed) We can move mountains...We are off to great places. Today is our day. Our mountain is waiting.. So...let's get on our way!"

Dr. Seuss, Oh, The Places You'll Go!

Leonie Demos

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HFV Membership Q&A

What does HFV do with my membership fees?

HFV value your membership and support. Membership fees allow HFV to continue to provide critical services to our community which would not be possible without your support. HFV provide grants and subsidies that help HFV members to access care and assistance.

What peer support can HFV members access?

As a member, you are invited to many peer support events throughout the year including:

- Community camp
- Men's retreat
- Gender- and age-specific activities
- Plus many opportunities to connect with others from our community

All events are heavily subsidised and are supported by the revenue gathered by the membership fees. You will also receive quarterly HFV magazine filled with member stories, the latest health related information and updates on all events offered on the HFV calendar.

What practical support can HFV members get?

Members can apply for financial support under the HFV Live Well or Emergency Funding Programs. Additional Financial Subsidies are available for other assisted programs such as cost of Ambulance subscriptions and ID bracelet or similar.

What does my HFV membership mean at a national level?

You receive automatic membership to the national body Haemophilia Foundation Australia (HFA) and may be eligible to apply for a subsidy to attend the bi-annual National Bleeding Disorders Conference.

What does HFV aim to provide for members?

HFV support our community to achieve the extraordinary and through your membership work in partnership with HFA to advocate to keep our community strong and benefit the best possible health outcomes.

When do I need to renew my HFV membership?

At the end of every financial year (late June), membership renewals are due. Please complete the attached paperwork or contact HFV if you require assistance.

AUTUMN EVENTS RECAP

Community camp

This year's community camp ran from 17-19 March at Lake Dewar Lodge in Myrning, with 17 families attending across the course of the weekend. It was great to catch up with new and old friends, especially some faces that we had not seen since before COVID. Sadly, high winds on Saturday meant that some of our activities had to be cancelled due to safety risks. The kids made the best of it, however, by floating a giant raft on the lake and engaging in an all-out water gun fight.

Next year, we are planning for camp to take place at Mill Valley Ranch in Tynong North - horses and barn dancing are sure to make an appearance!



Social climbing gym day

On Saturday 6 May, seven of us met for coffee and rock climbing at Hardrock Climbing in the Melbourne CBD. We were delighted to welcome three new adults with bleeding disorders into the HFV community - hopefully the heights did not scare them off!

If you are an adult who is interested in taking part in casual adventure and fitness activities, let Yarrow know at yarrow@hfv.org.au and he will put you on the list for similar events.

AUTUMN EVENTS RECAP

Men's retreat

A dozen men headed off from 12-14 May for a weekend retreat away. This year, the retreat took place at The Hive at Hepburn. Initial suspicion of the new venue was quickly replaced by excitement, and we hope to return for another trip next year. The overarching feedback from those who attended was that the retreat allowed them to relax in an environment where people understood haemophilia, build connections, and get tips and tricks from other guys on managing their health.



Ladies' day

On Sunday 21 May, our HFV ladies met up for a well-deserved pamper at True Thai Prahran. It was our first face to face catch up since Covid. The massages, whether back, neck, foot or leg were amazing and enjoyed by all! Afterwards the group headed out to catch up over lunch together. We were lucky to have a mix of long time HFV members, young parents, and everyone in between, including some mums, daughters and carers.

All in all, a successful and relaxing day out. And great to be able to re-establish those connections and support networks face to face. If you missed this event ladies, make sure to keep an eye out for our next catch up.



GETTING TO KNOW OUR YOUTH LEADERSHIP TEAM

with Ben Inglis



Tell us about your career and aspira- tions...

I work fulltime as a primary school teacher at the moment. Last year I taught a year 1 class and this year I am teaching year 2, which has been pretty cool.

When I was younger, I wasn't really sure what I wanted to do. Initially, I thought I wanted to become a doctor and go into haematology, but then I studied biomedical science and decided medicine wasn't for me.

I took a gap year and worked at a summer camp in the USA called "The Painted Turtle". That was one of the best things I've ever done in my life. Each week, we would have kids come who had a different medical condition, and that's where I learned about the field of "child life therapy" and decided I wanted to pursue that.

Child life therapy is about helping kids with medical conditions to develop healthy life skills. I found out that the way to get into that career in Australia is to teach for a few years in a school environment and then eventually transition to working for places like the RCH and certain non-profits,

who have specialist teams set up.

What are your hobbies?

In my personal life, I like to go rock-climbing with friends and play board games (not that I'm any good at them!). I got into both of those hobbies in the same way - through work. Getting a job at a rock-climbing place got me into climbing and getting a job at a board game store got me into games.

What are your core values?

I strongly believe in "being the change you want to see in the world." That sort of widespread change comes from actually living it. I try to learn and grow, and come at things from a place of kindness and understanding. I really want to feel like I can look back and be proud.

What was it like growing up with haemophilia?

I have moderate haemophilia A. We knew that my grandfather had haemophilia and I was diagnosed at birth. At the time, my mum was also described as being a "symptomatic carrier" - today we would just say she has "mild haemophilia" herself.

Growing up with haemophilia absolutely helped shape who I am today. I think

coming from the position of being a cisgender, Christian white Australian male, having haemophilia gave me a perspective on disadvantage that I otherwise might not have had access to. I've also received so much support from people from the different spheres in my life, which is part of what shaped my values. I really feel the drive to pay that support forward.

Has HFV helped shape you? Tell us about your leadership and achievements...

I'm on the HFV committee and run the youth team, which I do think has influenced me. I'm not too sure how I ended up in more of a leadership role in HFV - it just happened that way. I'd been so involved for so long that at a certain point, it became natural.

My proudest HFV achievement is probably the creation of the youth team. That was a big step forward in the right direction for HFV, and I was proud to be a part of that. One thing I've especially enjoyed about the blue shirts program is how we've come together and grown collaboratively.

A few years back, some of us wanted to set it in stone as an ongoing part of HFV. We decided to become more official and got some documentation together. That's helped us to have that agency to make decisions and give input on how we think

things should be.

What's next for the HFV youth program?

I would like us to work towards having a bit more power and agency within HFV and I guess I'd like to see us doing more things throughout the year. I'd also really like to see a youth team representative on committee. Ultimately, I just want to have it built up enough that when I'm too old to justify being a youth leader, the program will just carry on without me.

Why should young people consider getting involved?

The support that the community gives - there's nothing else that can fill that particular part of your life. Living with a bleeding disorder is so rare that having even one person in your life to talk to can make a big difference. Even with these new treatments, unfortunately things are still going to go bad sometimes. When that happens, there is no substitute for community support.

I want people to know that we're looking for more members for the youth team. Any young person thinking about it should absolutely give it a try. Every new perspective we bring on board helps make us stronger and better.



MELBOURNE 24 – 26 AUGUST 2023

21ST AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD AND RARE BLEEDING DISORDERS

The 21st Australian Conference on haemophilia, VWD & rare bleeding disorders will be held face-to-face at the Pullman on the Park, Melbourne, 24-26 August 2023.

Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss key issues and plan for the future.

Community Funding

Subsidies are available for HFV members to help cover the cost of conference registration fees. Some additional funds may be offered to subsidise other costs associated with conference attendance, such as travel and accommodation, as needed. Apply ASAP to give yourself the best chance of receiving funding.

Please note that funding cannot be guaranteed. HFV members from rural and regional areas will receive priority for travel and accommodation support. See the enclosed notice for more details.

Program

The Program committee is working together to put together a program that is interactive, educational and covers current and emerging issues and topics.

Topics include:

- New therapies in bleeding disorders, including gene therapy
- VWD
- Rare bleeding disorders
- Women and girls with bleeding disorders
- MSK (musculoskeletal) and ankle arthropathy
- Mild haemophilia
- Children and families
- Inheritance, genetics and family planning
- Making career choices
- Fitness and sport
- Pain
- Getting older
- Good health and wellbeing

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You can register for conference tickets online now at:
<https://tinyurl.com/HFAConf>





21ST AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD AND RARE BLEEDING DISORDERS

MELBOURNE 24 - 26 AUGUST 2023

Free Mythbusting Animation Workshop at ACMI

Perfect for creative kids! Have fun meeting others, help bust myths about bleeding disorders and learn how to animate.

- 12pm onwards, Saturday 25 August 2023
- ACMI Federation Square, Melbourne
- 10-16 years old
- Run by ACMI staff with HFA staff in attendance (parents/guardians welcome too!)

This workshop will coincide with the HFA Conference. If their parent/guardian is attending the conference, kids are welcome to come for the day - we will have an activity in the morning.

To express interest or find out more contact **Natashia Coco**:
ncoco@haemophilia.org.au or call 0403 538 109

The animations will be showcased during Bleeding Disorders Awareness Month



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HOW VAPING AFFECTS TEENS WITH A BLEEDING DISORDER



This article was originally written by Beth Levine for HemAware Bleeding Disorders Magazine in December 2022 and was adapted by Haemophilia Foundation Victoria for “The Missing Factor”.

What is vaping?

Vaping is hugely popular among young people today. More than 2 million U.S. students in grades six to 12 vape, with e-cigarettes being the most used tobacco product in youth, according to the 2022 National Youth Tobacco Survey.

Vaping is the use of an electronic device (e-cigarette) that heats a liquid into an aerosol that is inhaled. The liquid often has nicotine in it and can also contain THC (the ingredient in marijuana that produces the “high”) but this is less common in Australia. Even e-cigarettes that claim to be tobacco-free often contain some nicotine. E-cigarettes can look like cigarettes but can also be shaped like a USB flash device or a pen.

Signs of vaping

The Partnership to End Addiction says there are some signs that indicate your teenager might be vaping:

- Smell; many e-cigarettes add flavoring, which produces a light scent
- Strange packages showing up for your teen; unknown expenses to your credit card
- Increased thirst, loss of appetite, nosebleeds, and headaches
- Equipment around the house that you can't identify
- Cutting back on caffeine; vaping causes sensitivity to the stimulant
- Increased irritability and anxiety and difficulty concentrating

Health affects of vaping for teens

Vaping can be detrimental to growing bodies and minds. “There are many serious health effects, including coughing, wheezing, seizures, and vomiting. There is also a potential for severe lung injury,” says Pat Aussem, associate vice president of consumer clinical content development for the Partnership to End Addiction.

Truth Initiative, a public health organization devoted to preventing tobacco use and nicotine addiction, says nicotine can affect key brain receptors and make it easier for youths to become addicted. It can harm brain development, exacerbate depression and anxiety, and increase stress.

Withdrawal from vaping

Teenagers have susceptible brains and are at a very impressionable age. When they quit vaping, their bodies and brains must get used to the lack of nicotine in their system. This is called nicotine withdrawal. The side effects of nicotine withdrawal can be uncomfortable and can trigger further cravings for the substance. Common nicotine withdrawal symptoms include:

- Feeling irritable, restless, or jittery
- Having headaches
- Increased sweating
- Feeling sad or down
- Feeling anxious
- Feeling tired or groggy
- Having trouble thinking clearly or concentrating

- Having trouble sleeping
- Feeling hungry
- Having intense cravings for e-cigarettes

Haemophilia and vaping

Vaping products containing nicotine and THC have been associated with a type of lung injury that has its own name: e-cigarette or vaping use-associated lung injury, or

EVALI.

“Given reports of diffuse alveolar hemorrhage [bleeding in the lungs], there is concern that people with bleeding disorders would be at higher risk for hemorrhage and have increased severity of bleeding,” says Stephanie Prozora, M.D., pediatric medical director of the Yale Hemophilia Treatment Center. “Available data suggest vaping THC may specifically worsen bleeding risk.”

E-cigarette fact sheet for parents and teachers

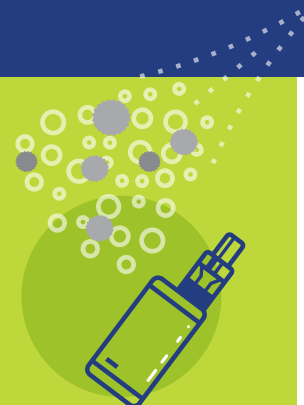


E-cigarettes cause serious health risks to teens.

Since the mid-2010s, there has been a **big rise in young people using e-cigarettes**, including teens who have never smoked. A Royal Children’s Hospital ‘Child Health Poll’ found over half of parents have never talk about e-cigarettes with their teen. Social media is being used by tobacco and e-cigarette companies to **sell e-cigarettes to teens and young adults**.

About e-cigarettes

E-cigarettes, also known as ‘vapes’, are electronic devices that **use batteries**. They work by heating a liquid until it becomes an aerosol that the user breathes in. Using an e-cigarette is commonly called ‘vaping’. Some people think the **mist** from vaping is a vapour, like steam. It’s not. It is really **an aerosol**, a fine spray of chemicals that enters the body through the lungs and small particles that can **get stuck in the lungs**.



How parents can help their teens

The first step in minimising the harm your child could be exposed to through vaping is by educating them early and often. E-cigarettes should be included in the conversations parents have with their teens around smoking, drugs, alcohol and other risk-taking behaviours. Additionally, there is research to suggest that young people are more likely to use nicotine products when those around them do too. Parents not using e-cigarettes, especially in front of children, can be a way of leading by example.

If your child is vaping and you are worried about their health, a good place to start is by connecting with their GP, paediatrician or HTC team to get some advice. Try to educate your teenager about the health problems vaping can cause, while remaining empathetic to the reasons that they may vape or the circumstances which may make it difficult to quit. The best plan is one that your teenager can stick to, so try to come together as a team. It can be valuable to work with health professionals who understand addiction and can explain the evidence on what helps people break habits like vaping.

If you notice that your teen has been vaping, encourage them to reflect on why they vape and how it makes them feel. Understanding this can also help parents find ways to support their child. Is your teenager bored? Perhaps help them find a new activity they might enjoy. Are they trying to self-medicate to address a mental health issue? Maybe they need to support from

Fast facts

1 | Legality of e-cigarettes

- Buying an e-cigarette or liquid with nicotine in it is **illegal** in Australia unless the person has a doctor's prescription.
- Nicotine-containing e-cigarettes and liquids can only be sold to people with a **valid prescription** in pharmacies.
- In Victoria, e-cigarettes and liquids that don't contain nicotine can be sold in shops, but it is **illegal to sell them to a person under 18 years old**.

2 | Safety


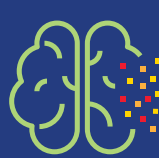
- Most e-cigarettes and e-liquids that don't show nicotine on their label in Australia **do, in fact, have nicotine**.
- There are **no quality or safety standards** for e-cigarettes or nicotine-free liquids, meaning their make, ingredients and labels are not regulated or checked.
- E-cigarettes can **explode** or catch fire.
- E-cigarette liquids can cause poisoning if swallowed.

3 | Detecting e-cigarette use

- E-cigarettes come in all shapes and sizes. They can look like a **highlighter**, a **pen** or **USB**. Some can be **disposable**, and some are small enough to fit into a pocket or a pencil case. An e-cigarette device can be identified by taking the cap off the item to see if it has a mouthpiece.
- Not all e-cigarettes release an aerosol that can be seen. The easiest way to detect e-cigarette use is if there is an **unexpected smell in the air** from e-cigarette flavouring. Teens tend to use fruit or sweet flavours, so this scent is usually sweet.

4 | Harms of e-cigarettes

- Nicotine **harms the way teenage brains grow**, which may affect memory and concentration.
- Teens become more easily and **rapidly addicted to nicotine** than adults, and those who use e-cigarettes are more likely to start smoking cigarettes.
- The short-term health effects of e-cigarette use can include vomiting, nausea, and lung injury.
- The long-term health effects are not yet known; however long-term impacts could include an increased risk of **cancer, heart disease, or lung disease**.
- It is the wide range of chemicals, regardless of nicotine content, that likely cause harm.



For more information visit quit.org.au/teenvaping

a mental health professional like a therapist. Are they feeling pressure to fit in with peers? Give them an out: If they are with someone who is vaping and they're uncomfortable, have them text you a code, and you can call right back with an excuse to pick them up. There may be unexpected ways you can help your teenager address their vaping.

If your child is addicted to vaping, they may need help to quit. While a GP is a good

first port of call, young people can also call Quitline to receive multisession, individually tailored behavioural support provided by skilled cessation counsellors. Quitline referrals can be made by phone from anywhere in Australia on 13 QUIT (13 78 48) or online at the Quit Centre:

www.quit.org.au

WRITERS GROUP

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16 JUNE 2023

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DONCASTER LIBRARY



We are inviting new or emerging writers aged 18–25 years with disability from Whitehorse and/or Manningham to join our free writers group that will run over 8 months as part of Writeability Goes Local.

Guided by local mentor, Jenny Hedley, you will have a safe space to explore writing about whatever you choose.

You will improve your writing skills through guided exercises and have the chance to workshop your writing if you choose. Award-winning writer Beau Windon will present as a guest author in session 5.

To register visit the
Writers Victoria
website:
[writersvictoria.org.au/
WMLwritersgroup](https://writersvictoria.org.au/WMLwritersgroup)

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NEW SIMPLE HAEMOPHILIA TESTING GUIDE FOR WOMEN AND GIRLS

Explaining genetic testing and factor level testing simply

Unsure about genetic testing and factor level testing in haemophilia and how it works in women and girls?

Haemophilia Foundation Australia has published a new education resource, Haemophilia testing in women and girls: a guide to answer these questions simply and clearly.

The resource is aimed at women, girls and parents of girls and uses relatable stories, infographics and diagrams to tackle some complex information in an accessible way.

Some questions the resource can help you understand

- How does a woman or girl know if she is affected by haemophilia?
- What are genetic and factor level tests?
- Who should have these tests and when?
- How is haemophilia passed on in a family - and what if there is no family history?
- Why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the education resource in collaboration with women and parents in the Australian community, Haemophilia Treatment Centres and genetics and legal experts. We would like to thank everyone involved for their advice and creative ideas!

We invite you to take a look at the resource - and pass it onto anyone you think would find it helpful.

How can you access the new resource?

Visit the HFA website page:
tinyurl.com/haemophilia-testing-simple

- Download the entire resource
- Read it online magazine-style (ISSUU)
- Download specific sections, eg genetic testing and counselling.

Look out for the web page version - coming soon!

To request print copies for free

- Email HFA at:
hfaust@haemophilia.org.au
- Or call 0398857800.

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Haemophilia testing in women and girls

Genetic testing | Factor level testing

A guide



HAEMOPHILIA FOUNDATION AUSTRALIA



The steps in genetic testing



1a. Information, discussion and counselling

You will have the opportunity for discussion with a haemophilia specialist and/or genetic counsellor before giving permission to have the test.

1b. Mapping the family tree

They will look at your family tree with you to identify other family members who may have the gene alteration.



2. Giving consent to having the test

You will be asked to sign a consent form for the genetic test. You can choose not to go ahead with genetic testing or withdraw your consent at any stage before the result is issued by the laboratory.

A genetic test for an obligate carrier is also a paternity test and this needs to be part of the discussion.

If the testing is for your daughter, it may need to be delayed until she is old enough to give informed medical consent herself. You may choose to only have factor level testing in a child.

World Hepatitis Day

28 July 2023

In July 2023 Australian landmarks will be glowing green to raise awareness about eliminating viral hepatitis. World Hepatitis Day is marked internationally on 28 July and is one of the World Health Organization's nine official global public health days. Green is used by the global NOhep movement - the colour of life, vitality and progress.

World Hepatitis Day is an opportunity to come together to step up efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. Once again, the theme in 2023 is Hepatitis can't wait.

Many people don't know that they have hep C. For example, you could be at risk if you have a bleeding disorder and ever had a blood product before 1993.

Or some people have been cured but still need follow-up for their liver health, especially if they have cirrhosis.

Do you think this might be you? Or someone you know?

By talking to our friends, family or a doctor about testing, treatment and liver health checks we can work towards the goal of viral hepatitis elimination by 2030.

On World Hepatitis Day we are reminded not to wait - know your hep C status, have treatment to cure hep C, where possible, and follow up on your liver health after treatment.

Look out for more information and activities on our website and social media in the week leading up to 28 July.



FIND OUT MORE

Australian World Hepatitis Day website - www.worldhepatitisday.org.au

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

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Notices & Information

IT'S TIME TO RENEW YOUR HFV MEMBERSHIP

With the end of financial year approaching, it is time to renew your HFV membership if you have not done so already.

Please complete the enclosed membership application form and send it to HFV in the included replied paid envelope. Please do not forget to include your personal details on the form.

If you require any assistance or have not received a membership form, please let our office know as soon as possible. Our contact details are:

13 Keith Street
Hampton East VIC 3188
Phone: 03 9555 7595
Mon - Thurs 8.30am - 4.30pm
info@hfv.org.au

We look forward to another year in service of this wonderful community.

WOULD YOU LIKE TO JOIN OUR COMMITTEE?

Have ideas about how HFV should be run?
Want to help advocate for other people?

We are accepting expressions of interest (EOI) now for 2023/2024 Committee of Management (COM) positions.

Requirements:

- Lived experience with a bleeding disorder (personally or through family/friends)
- Availability to attend 6-8 evening Zoom meetings per year, typically on Tue/Wed
- Motivated to assist in decision-making, including around sensitive topics

We welcome EOI from a diversity of ages, lived experiences, and perspectives.

Please email your EOI to:
info@hfv.org.au

BLEEDING DISORDERS CONFERENCE SUBSIDIES

Did you know we offer subsidies to assist members in attending the bi-annual National Bleeding Disorders Conference? HFV are now accepting applications via the enclosed form. If you have any questions or concerns, do not hesitate to get in contact with the HFV team.



13 Keith Street
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PATRON: Dr Alison Street AO

EXECUTIVE ASSISTANT

Andrea McColl andrea@hfv.org.au
COMMUNICATIONS COORDINATOR
Yarrow Ruane yarrow@hfv.org.au

COMMITTEE OF MANAGEMENT:

PRESIDENT Leonie Demos
VICE PRESIDENT Dan Korn
TREASURER Bernard Paes
EXECUTIVE MEMBER Donna Field

GENERAL COMMITTEE:

Ben Inglis
Chris Phong
Zev Fishman

VICTORIAN HAEMOPHILIA
TREATMENT CENTRES



Henry Ekert

Haemophilia Treatment Centre

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

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Erin Krake | Clinical Nurse Consultant
Julia Ekert | Administrator/Data Manager
Nicola Hamilton | Physiotherapist

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](mailto:(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:

All current financial members can apply for Live Well Funding for any item or activity which the applicant anticipates will contribute to a positive health outcome. Priority may be given to funding applications for items or activities related to the management of bleeding disorders and associated health conditions.

Care and Counselling:

This is available through your treatment centre.

Magazine:

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 2022, 11 members attended the retreat, including a Tasmanian! Many promised 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. If you have an idea for a ladies day, let us know! We are always looking to try new things.

YOUTH GROUP & BLUE SHIRTS

After a successful reunion at 2022 community camp (with lots of new leaders coming on board) the Blue Shirts will be meeting up in September 2022 for an Amazing Race through the Melbourne CBD. HFV have lots of leadership opportunities available for young people looking to have fun and challenge 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. Recently, several families met for an indoor climbing day. Check out our events schedule for upcoming kid-friendly activities.

A woman wearing a red baseball cap, sunglasses, and a black top with a floral pattern is speaking into a microphone. She is standing outdoors at what appears to be a community event or gathering. In the background, there are other people, some wearing red caps, and a body of water. A red banner with white text is overlaid on the image.

THANK YOU LEONIE!