

SUMMER 2024

THE MISSING FACTOR

HAEMOPHILIA FOUNDATION VICTORIA



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President's Report

Hello everyone,

I hope this message finds you all healthy, happy, and well into your summer and holiday-season celebrations. This year I'm looking forward to having some of my extended family law staying with us over Christmas, and a little later we'll have other family visit when they come down to see the Australian Open.

The extra time I'll spend with my extended family aligns with a similar trend for HFV this year. Looking back at the end of 2023, we were concerned about declining attendance at some events and late cancellation of others. It was hard to decide if it was something about the events we chose to put on, the way we ran them, or simply an extended hangover from pandemic lockdowns.

I'm pleased to report that 2024 has finally reversed that trend and we're seeing more of you now at our in-person gatherings. It's critically important to me that people from all across the bleeding disorder community feel connected to each other and to HFV. While we live in an age of instant communication across nearly any distance, the idea to pick up the phone and ring around for advice when you can't reach your GP after-hours depends on us

establishing trust and friendships in the first place.

In my experience those bonds grow quickly and strongly after first forming at gatherings like our Bleeding Disorders Awareness Month walk around Albert Park Lake or our AGM Picnic. And these gatherings are especially important to maintaining our community ties now that we don't see each other so often in hospital waiting areas. So it's wonderful to see attendance rising again, and I hope we can carry that momentum into 2025.

On that topic, I'd like to highlight that our next Family Camp is just around the corner and registration will open soon for our March 2025 edition! We will be returning to Mill Valley Ranch in Tynong North. I hope all of you who took up lassoing last year have been practicing and can really wow the crowds with your tricks this time around.

In addition to the events which have their own reports in this magazine, I also want to note our 70th anniversary luncheon. We were very happy to gather some past officers and health professionals, especially Prof. Henry Eckert, and reflect on how things have changed for the bleeding disorders community through the years. It was sobering

to look back on just how much bleeding disorders care and our community have evolved since HFV was founded in 1954, especially when you consider that 70 years was literally one lifetime ago - the average adult life expectancy for Australia at that time was 69.6 years!

Before I sign off, I would especially like to thank Ann Roberts and Leonie Demos for their work with HFV. Leonie and Ann are stepping down from the Committee of Management this year and each has been president of our foundation in the past. I think it has been an exceptionally long time since the committee didn't have at least one of them volunteering for HFV, and without them we could not be in the strong position we find ourselves in now. Their guidance will be sorely missed.

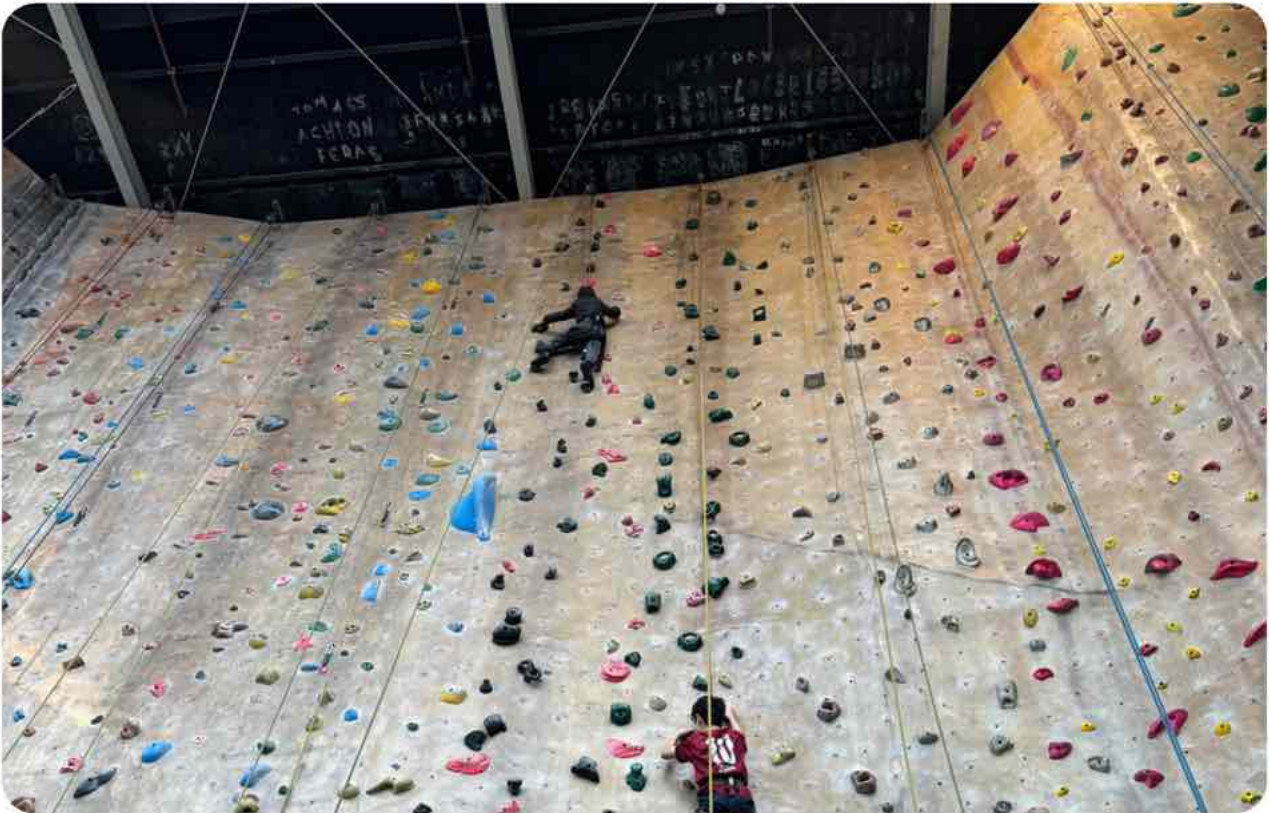
That's all from me. Have a great summer, enjoy your holidays, and I'll see you in 2025.

Cheers,
Dan



Scaling new heights

HFV's school holiday climbing adventure



On the 25th of September, the atmosphere at HardRock Climbing CBD was electric as HFV organised and hosted an thrilling school holiday outing for its members. Children in primary and secondary school, along with their families, came together to embrace challenges, foster confidence, and create a strong sense of community.

OVERCOMING FEARS

The day was filled with moments that showcased the power of support and encouragement. Some climbers, initially overwhelmed by the height of the walls, faced their fears with determination. Supported by a youth leaders and other climbers, found the strength to conquer the climb, transforming anxiety into triumph. This powerful display of perseverance highlighted the importance of having support when facing challenges.

THE POWER OF PEER SUPPORT & CAMARADERIE

Another inspiring moment came from Fefe, a courageous primary school student who became the first to conquer the challenging BIG WALL section. His success was not just a personal achievement; it served as a powerful reminder to everyone present that with grit, encouragement, and supportive peers, we can all rise to the occasion and shatter the limits we place on ourselves.



The camaraderie among the children was remarkable throughout the day. They cheered for one another, offering high-fives and words of encouragement as each climber tackled the walls. The spirit of peer support was crucial, creating an environment where everyone felt empowered to push beyond their comfort zones. Together, they celebrated each victory - small and large, proving that when we lift each other up, we can achieve remarkable things. The importance of peer support cannot be overstated; it not only enhances individual confidence but also fosters a community of encouragement and resilience.

GRATITUDE FOR OUR SUPPORTERS

The day wouldn't have been possible without our amazing Blue Shirts, Ben Inglis and Chris Phong, whose unwavering support made a world of difference. Their enthusiasm and experience empowered,

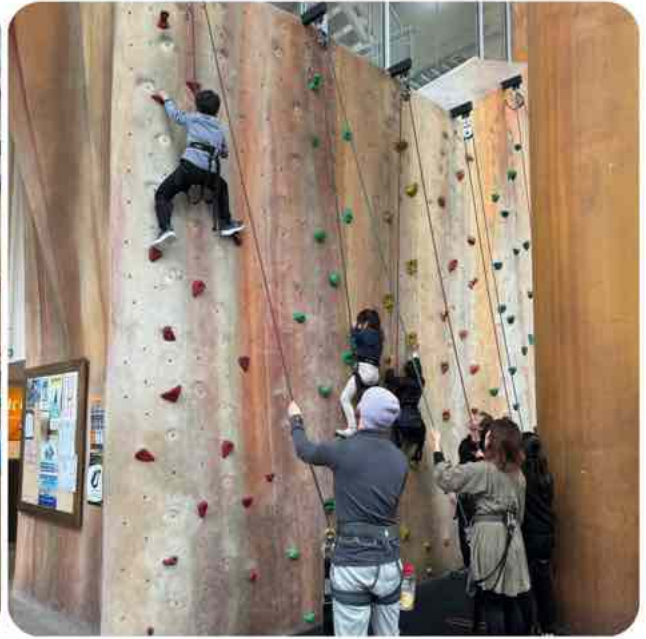
every young climber, reminding them that they are capable of achieving greatness. One mother shared her own transformation, expressing how she never would have had the courage to bring her son to such an event before. Watching him face the mental, emotional, and physical challenges of climbing was truly eye-opening, illustrating the strength that community can provide.



CELEBRATING ACHIEVEMENTS

As the climbing session came to a close, families gathered for a joyful coffee and lunch catch-up. This was more than just a meal; it was a celebration of achievements and connections forged through shared experiences. Laughter echoed, stories were exchanged, and the importance of support—both from peers and parents—resonated deeply within the group.

HFV's school holiday outing at HardRock Climbing CBD was a great reminder of what we can achieve when we work together. Let this day motivate us to keep pushing ourselves, facing challenges, and reaching new heights—one step at a time. Let's keep climbing!



KEY EVENT DATES - KIDS & YOUTH

5th of April - Youth Day Out

9th of July 2025 - School Holiday Program

3rd of October 2025 - School Holiday Program



Bleeding Disorders Awareness Walk

A day of unity and support



On 27th October 2024, the Bleeding Disorders Awareness Month (BDAM) walk took place at Albert Park Lake, bringing together over 60 members of the bleeding disorders community for a day of solidarity, education, and fun. It was a day filled with meaningful conversations, shared experiences, and a powerful sense of unity.

The day began with members, families, and friends arriving at the picturesque Albert Park, all wearing red to symbolise awareness for bleeding disorders such as haemophilia and von Willebrand disease. This unified display of red shirts and hats created a striking visual that spoke to the power of community and the collective commitment to spreading awareness about these conditions. The sight of so many people walking side by side, dressed in the

same colour, was a testament to the strength of the community and the importance of raising awareness on a larger scale.

THE WALK

After a brief welcome and introductions, the group set off on a walk around Albert Park Lake. As the participants strolled along the lake's path, the sense of unity and support was visible. The walk was not just a physical activity, but a powerful

opportunity to share personal stories, provide encouragement, and learn more about the challenges faced by those living with bleeding disorders. Members walked alongside family, friends, and fellow members, demonstrating the strength of a supportive community that goes beyond medical care. The walk itself was leisurely, with plenty of time for members to connect, chat, and reflect on their experiences. The serene surroundings of the park, combined with the sense of togetherness, allowed for a reflective atmosphere that encouraged bonding and understanding.



THE POWER OF CONNECTION & FOOD

As the walk came to an end, participants made their way to the BBQ station, where a sausage sizzle awaited. The aroma of sizzling sausages filled the air, and it wasn't just about enjoying a delicious meal—it was a chance for everyone to sit down, relax, and continue the conversations started on the walk. It was a moment for people to reconnect, share experiences, and continue the conversation started on the walk.

“I always look forward to the sausage sizzle,” said, a long-time member of the community. “It’s such a simple thing, but it brings us together. It’s about more than just the food; it’s the time spent with people who understand what you’re going through.”

The event also provided an opportunity to catch up with familiar faces and meet new people, further solidifying the sense of community. As the sausages were served and enjoyed, conversations flowed easily, and members exchanged advice, support, and hope for the future.

RAISING AWARENESS & MOVING FORWARD

The Bleeding Disorders Awareness Month walk was not just an event—it was a demonstration of the strength, resilience, and unity of the bleeding disorders community. Through their participation, the members highlighted the challenges faced by those living with bleeding disorders and made a strong statement about the importance of raising awareness.

Our first Bleeding Disorders Awareness Walk took place in October 2017, with this year's success. We hope the BDAM walk will continue to grow in numbers. As the day ended, there was a strong sense of pride. Over 60 people had come together in solidarity, united in their commitment to raising awareness.

The sight of so many in red walking together left a lasting impression. For the bleeding disorders community, 27th October 2024 was a day of connection, support and empowerment, one that will resonate long after the event.



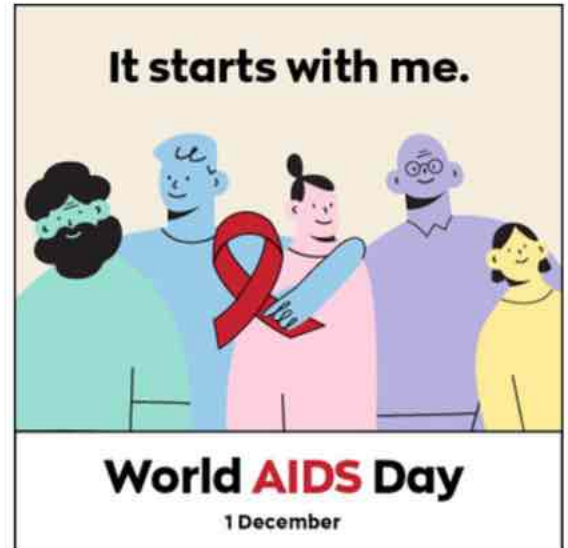
WORLD AIDS DAY

World AIDS Day is marked internationally on 1 December.

It's a day for Australians to:

- show their support for people living with HIV
- raise awareness about prevention, treatment and care
- eliminate stigma and discrimination around HIV
- remember and honour the people we have lost to HIV.

Wearing a red ribbon is one way people show their commitment to HIV remembrance, awareness and support for people living with HIV.



In 2024 the global theme asks us to consider how we will help - to uphold human rights and support those who are marginalised or discriminated against. In Australia the national theme asks us to be proactive with It starts with me.

HIV AND THE BLEEDING DISORDERS COMMUNITY

HIV has been part of our history and continues to be part of our community's experience.

In the mid-1980s some adults and children with bleeding disorders acquired HIV from their plasma-derived clotting factor treatment products. Some lost their lives to HIV while others live with HIV today. Today treatment products are much safer: the risk of bloodborne infection from products manufactured from blood is extremely low. But HIV has had a profound effect not only the people with HIV, but also those close to them, their health professional carers and the bleeding disorders community generally.

In Australia people with bleeding disorders drew on the resilience that was already a strong feature and resolved to respond to HIV as a community, taking on effective advocacy around safer treatments and providing support.

TAKING A RIGHTS PATH

In 2024 the Joint United Nations Programme on HIV/AIDS (UNAIDS) calls on us to take a rights path to HIV. Central to this are the themes of Inclusion. Respect. Equity. If we are to take on the commitment of It starts with me, what does this mean for the bleeding disorders community?

What does Inclusion. Respect. Equity. mean to you?

For World AIDS Day last year, our community members Neil, Mike and Anth shared short reflections on these themes. We feel they are still relevant and meaningful and worth republishing. We share them again with their permission.

Neil

I've been very open about my HIV status for years now and I've been humbled by the respect shown to me by everyone I've told. Being free to answer questions and break down any fears has only helped my inclusion in social circles.

Mike

When I see the word 'inclusion', I think of how the bleeding disorders community and the HTCs have come together to deal with HIV.

Haemophilia when I was growing up in the 1950s, 60s and 70s was life threatening and I required many treatments.

The 1980s was a catastrophic period. HIV caused a lot of devastation and worry to me and my wife personally. It also brought a lot of families together, and it was this support that helped us to survive this period in our lives where so much was unknown.

We were very fortunate to have great team of doctors, nurses and a psychologist who were very understanding and supportive, and we would not have survived this time without the tireless work from HFA.

Anth

For me, the themes of inclusion, respect and equity provide a checklist of game-changing ideals in global efforts to a) eliminate HIV transmission, and b) care for people living with HIV. Without a sharp uptick in these areas, the world's poorest and least powerful communities will continue to be disproportionately affected.

But what do these words mean to our bleeding disorders community in Australia? Those of us who have lived with HIV for over 40 years, and those of us who have seen loved ones succumb? I often feel like our part in the story of HIV/AIDS gets forgotten. While the increasing dissociation of HIV/AIDS and bleeding disorders creates safety for us, it denies our truths and remarkable achievements too.

Whether you mark World AIDS Day privately or publicly, or not at all, please know that you remain part of a community that is extraordinary for its resilience and dignity in the face of bloodborne viruses.

[READ MORE](#)

Visit www.worldaidsday.org.au for more information about World AIDS Day in Australia.

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Parenting a teenager with a rare bleeding disorder



How is parenting different if your child has a rare bleeding disorder? Elizabeth's daughter Grace has Glanzmann thrombasthenia, a rare hereditary platelet function disorder. Elizabeth spoke to HFA about the strategies her family has developed to manage the risks for a teenage daughter who has unusual bleeding problems

'Grace is our only daughter. She is a typical teenager. She loves life, she loves fishing and camping and loves being outdoors.'

Grace has Glanzmann thrombasthenia. 'She has platelets but they don't function properly, so she has a treatment plan of "don't get hurt"!' explained Elizabeth. While risk management is very important, Grace has a medical treatment plan for her bleeds with a variety of treatment

products and a specific treatment plan for her periods that has been worked out with her gynaecologist.

THE CHALLENGES OF RISKS

Grace's diagnosis as a baby was very unexpected and Elizabeth and her husband have developed strategies to manage Grace's bleeding risks over time as she has grown up. Initially it was very challenging: 'we were first time parents and it felt like it was one long learning curve.'

Now that Grace is a teenager, both she and her parents have a wealth of childhood experiences to draw on and her parents feel it is important to support her in developing independence and taking responsibility for herself - but also to enjoy her life.

‘Grace just goes about life and has fun and always assesses her risk for injury.

‘So she can go for a run and be careful about it, but she is not going to play footy or even basketball or netball. She goes and finds things that she can do. When she wants to try new things, we try to make it happen.

‘But Grace makes all her own decisions now. She covers academic and I cover bleeding until she feels comfortable taking over that. I help her with her appointments and I remind her if I feel some of her decisions about what she’s doing is a risk for her health, but she understands what she can do. She has just learned it along the way.’

MANAGING SCHOOL

What is a ‘contact sport’ for Grace? With a new year starting, Elizabeth thought about what the letter to Grace’s new teacher should say and decided to be very direct:

‘I said, Grace will let you know if she is able to participate in what you may or may not consider contact sports. But you need to know that when she is sitting out, she needs to be safe too because she always gets hit in the face with a ball, whatever sport she is playing.’

It has been important to work with the school to align what everyone thinks is acceptable. For Grace, this approach has resulted in some strategies that work well for her - to streamline her treatment so she doesn’t feel like she is missing out on her classes or feeling like ‘the odd kid who is sitting there with an icepack’. For example:

- A red flag on her file and emergency plans and strategies in place
- An ice pack in the staff freezer with her name on it
- Quiet places she can go to ice or treat her bleed or injury
- A first aid kit in Grace’s bag and a first aid kit for her in the office.

A SUPPORTIVE FRIENDSHIP NETWORK

Accidental injury when children are growing up is inevitable. But having a bleeding disorder can be challenging at school, where there can be children who think it is fun to hurt other children. With Grace they could see a result straight away:

‘If they push her over and she skins her knee, she bleeds like a sieve and has an egg.

‘She has amazing friends now who rally around her. When she fell over and she couldn’t really walk, they got an ice pack for her and went and got a teacher.’

Being careful extends to playing sport and socialising as well.

‘When she does sports or when she goes out with her friends, she has to be out with more than 2 friends in case she falls over and hurts herself.’

MANAGING AT HOME

At home there is a balance.

‘What’s important is finding what works for you in a routine and inside and outside the house.

‘We’re relaxed about some things and strict on others. And we have rules - like she needs to be safe about what she’s doing.

‘I do notice that we do things differently. She is only allowed to cook when we are at home in case she gets a burn or cuts herself by accident. She loves to cook and she is a good little chef.’

Keeping fun in her life has also been important.

‘If you have a bad day and you have something fun to do, you can just go and do it.

‘Grace always wanted a pond and she now has one. So she can go out there every day and feed her fish and play with her fish, because they love coming up to eat off her hand.’

OPEN COMMUNICATION

With a bleeding disorder open communication is crucial. Some bleeding episodes can have very serious consequences and recovery can take weeks longer if the bleed is not treated quickly.

‘When she does have a bleed she really needs to tell me so we can fix it. We nearly missed a head injury because she was trying to protect her friend - and lied and said “I fell over because I walked into a pole” but really she had fallen over and

hit her head on cement when her friend was angry and pushed her.’

They have also been fortunate to have a good family friend whom Grace trusts.

‘If your child is having a bad day and they just don’t want to talk to you, it’s important they have someone that both you and they are comfortable with.

‘Grace is a teenager - I think she always talks to me, but she might not. But she has a friend of mine that she adores and my friend absolutely adores her. And if there’s anything she can’t tell me or her dad, she can tell her.

‘But Grace is such a good kid. Most days the worst thing she does is roll her eyes at me. When you’re a parent and you complain that your daughter rolled her eyes at you, you’re pretty lucky!’

Ultimately for Grace and her parents it’s about living life and finding the positives - ‘the things to look forward to.’ ‘We just feel normal. It’s one of those things in life. And for Grace, it’s just being careful.’

**Elizabeth and Grace are not their real names*

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Stock image: Karolina Grabowska for Pexels.com*

HFV FAMILY CAMP 2025!

We are delighted to announce that our 2025 HFV Family Camp venue and dates are confirmed! Save the date and keep an eye out for our registration link.

- *Early bird prices*
- *Day-visits are available for new families*

Where: Mill Valley Ranch
When: 21-23 March 2025
Who: Member families

Please see camp insert flyer for more details & FAQs

New VWD fact sheet

Looking for some simple information about von Willebrand disease (VWD) to share with others?

HFA's new Von Willebrand disease (VWD) fact sheet has answers to a range of FAQs with the very latest information:

- What is VWD? How do you get it?
- What are the symptoms and types?
- How is it diagnosed and treated?

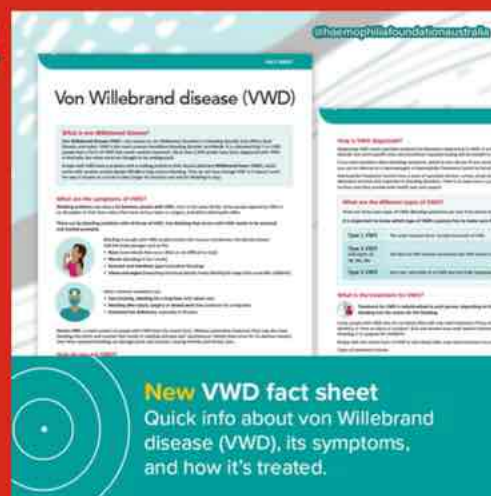
Share it with your family - or keep it on hand for new doctors or school or other situations where you want to give a quick explanation.

And don't forget to talk to your Haemophilia Treatment Centre (HTC) to keep up-to-date with treatment options for VWD.

Download the fact sheet from the HFA website - www.haemophilia.org.au/resources

Or contact HFA for print copies:
E: hfaust@haemophilia.org.au
T: 03 9885 7800

A big thank you to the health professional experts and the HFA VWD consumer focus group for their contributions and advice.



Von Willebrand disease (VWD)

What is von Willebrand disease?

Von Willebrand disease (VWD – also known as *von Willebrand disorder*) is a bleeding disorder that affects both females and males. VWD is the most common hereditary bleeding disorder worldwide. It is estimated that 1 in 1,000 people have a form of VWD that needs medical treatment. More than 2,500 people have been diagnosed with VWD in Australia, but many more are thought to be undiagnosed.

People with VWD have a problem with a clotting protein in their blood called **von Willebrand factor (VWF)**, which works with another protein **factor VIII (8)** to help control bleeding. They do not have enough VWF or it doesn't work the way it should. As a result it takes longer for blood to clot and for bleeding to stop.

What are the symptoms of VWD?

Bleeding problems can vary a lot between people with VWD, even in the same family. Some people experience little or no disruption to their lives unless they have serious injury or surgery, and others bleed quite often.

There can be bleeding problems with all forms of VWD. Any bleeding that occurs with VWD needs to be assessed and treated promptly.



Bleeding in people with VWD usually involves the mucous membranes, the delicate tissues that line body passages such as the:

- **Nose** (nose bleeds that occur often or are difficult to stop)
- **Mouth** (bleeding in the mouth)
- **Stomach and intestines** (gastrointestinal bleeding)
- **Uterus and vagina** (heavy/long menstrual periods; heavy bleeding for longer than usual after childbirth).



Other common symptoms are:

- **Easy bruising, bleeding for a long time with minor cuts**
- **Bleeding after injury, surgery or dental work** that continues for a long time
- **Anaemia/iron deficiency**, especially in females.

Severe VWD: a small number of people with VWD have the severe form. Without preventive treatment they may also have bleeding into joints and muscles that results in swelling and pain and 'spontaneous' bleeds (that occur for no obvious reason). Over time repeated bleeding can damage joints and muscles, causing arthritis and chronic pain.

How do you get VWD?

VWD is usually inherited. It occurs when there is a change (*mutation*) to the VWF gene. This gene change is passed down from parent to child. Some people with the VWF gene change have no bleeding symptoms while others do.

The VWD inheritance pattern is *autosomal* and affects both males and females in equal numbers. Most often there is a 1 in 2 chance of a parent passing the gene change onto their children. In some other cases, both parents can have the gene change, often without symptoms. If their child inherits the gene change from both of them (a 1 in 4 chance), the child will usually have the severe form of VWD.

Sometimes there is no family history of VWD. This is because there was a VWF gene change that occurred during reproduction before the baby was born. The person born with the VWF gene change can pass it onto their children.

How is VWD diagnosed?

Diagnosing VWD needs specialist medical and laboratory experience in VWD. A screening test may suggest a bleeding disorder but more specific tests and sometimes repeated testing will be needed to make an accurate diagnosis.

If you have questions about bleeding symptoms, speak to your doctor. If your doctor thinks your symptoms suggest VWD, you can be referred to a haematologist or Haemophilia Treatment Centre for blood tests.

Haemophilia Treatment Centres have a team of specialist doctors, nurses, social workers/psychologists, physiotherapists and laboratory services with expertise in bleeding disorders. There is at least one in a public hospital in every Australian state or territory and they provide both health care and support.

What are the different types of VWD?

There are three main types of VWD. Bleeding symptoms can vary from person to person within each type.

It is important to know which type of VWD a person has to make sure they receive appropriate treatment.

Type 1 VWD	The most common form. Usually low levels of VWF.
Type 2 VWD (sub-types 2A, 2B, 2M, 2N)	The level of VWF may be normal but the VWF doesn't work properly.
Type 3 VWD	Very rare. Very little or no VWF and low FVIII. Symptoms are more severe.

What is the treatment for VWD?



Treatment for VWD is individualised to each person, depending on their VWD type, the severity of their bleeding and the reason for the bleeding.

Some people with VWD who do not bleed often will only need treatment if they are having medical procedures, surgery, dentistry or have an injury or accident. Girls and women may need special treatment plans to manage heavy menstrual bleeding or to prepare for childbirth.

People with the severe form of VWD or who bleed often may need treatment to prevent bleeding called *prophylaxis*.

Types of treatment include:

- tranexamic acid
- synthetic hormones (eg, desmopressin/DDAVP)
- hormone treatments for females (eg, oral contraceptives or IUDs)
- VWF or VWF/FVIII clotting factor concentrates
- other new treatments, eg, that mimic the way factors work in the body.

Speak to your haematologist or pharmacist before taking medicines that may interfere with clotting, including aspirin, non-steroidal anti-inflammatory drugs (eg, ibuprofen), or other blood thinners.

For more information

Speak to your **doctor**, your local **Haemophilia Treatment Centre (HTC)** or visit www.haemophilia.org.au. In an emergency, seek medical attention promptly. Ask to speak to *the haematologist on call* at your local HTC hospital for specialist advice.

Reviewers: HFA VWD consumer Focus Group (individuals not named for privacy reasons). Australian Haemophilia Centre Directors' Organisation: A/Prof Chris Barnes,

Dr Amanda Davis, Dr Sam Hitchins, Dr Stephanie P'ng. ANZ Haemophilia Psychosocial Group: Jane Portnoy. ANZ Physiotherapy Haemophilia Group: Cameron Cramey, Nicola Hamilton, Alison Morris. Australian Haemophilia Nurses' Group: Janine Furmedge, Penny McCarthy, Megan Walsh.

Important Note:

This fact sheet 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.

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WELCOME TO TANYA



Welcome to Tanya

Tanya Gruenwald is the psychologist and newest member of the Haemophilia Treatment Team at The Alfred.

She is working two days a week, on Tuesdays and Thursdays.

Tanya came to us from the Children's Hospital where she worked in the Pain Team. She has a special interest in Chronic Pain and Mental Health.

We are already enjoying the benefits of having Tanya in the team, and invite our patients to book in with Tanya or talk to the team about coming to see Tanya.

Tanya has an interest in Music. She enjoys listening to music and used to play the trumpet but hasn't played for many years. She would need some convincing to play again.

HFV AGM & Christmas Picnic



On Saturday, 17th of November 2024, HFV committee, staff, members and their families gathered at Werribee Zoo for the HFV's Annual General Meeting (AGM) Dan HFV President, addressing our members.

The day began at 9am, with families arriving and settling in at Chongola Hut to drop off their lunches. Members then had the chance to enjoy the zoo's attractions, including the safari bus tour and animal enclosures. The morning provided a great opportunity for members to catch up meet new faces, and enjoy the zoo together. The atmosphere was relaxed, with families and children exploring, chatting and making the most of the lovely morning weather.

As the AGM was set to begin at noon, the weather took a dramatic turn. Strong winds picked up, and light rain started to fall, making it clear that the afternoon would be more unpredictable. Fortunately, the meeting was held under the cover of Chongola Hut, where everyone remained comfortable and dry despite the elements around us. The brief weather change didn't dampen spirits, and the sense of community remained strong throughout the event.



PRESIDENT'S & TREASURER'S REPORT

The AGM officially began with the President's Report which reviewed HFV's achievements over the past year. The President highlighted the growth in the success of volunteer/committee supported projects, and the ongoing commitment to supporting and empowering members. The President, Dan Korn noted that HFV had maintained a stable financial year, with continued support from memberships, subscriptions, and donations. Thus supporting HFV programs. We are especially grateful to Flora and Frank Leith Charitable Trust, for the generous \$10K donation for HFV Camp 2024.

We continue to receive funding from the State Government for our premises, staff and key health promotion. We are incredibly appreciative for their endless support.

The financial outlook for the year ahead is positive, ensuring that HFV can continue to grow and expand its services.

There was particular emphasis on the importance of peer support within the community and was encouraging to see so many members eager to take on leadership roles, helping guide HFV's direction and ensuring its continued success.

CELEBRATING COMMUNITY: RAFFLES & PRIZES

After the formal proceedings, the community gathered for a raffle, where members had the chance to win a variety of exciting prizes. Santa's helpers (AKA HFV staff) with Christmas sacks handed out special Christmas treats for all the children.

The highlight of the afternoon was the community lunch, where members shared dishes from different cultures. The lunch was a wonderful reflection of the diversity of the community, with food from around the world. The warmth of the gathering, created a welcoming and inclusive atmosphere.



LOOKING AHEAD: GET INVOLVED

As the AGM concluded, there was a renewed sense of excitement for the year ahead. With the election of new committee members and the plans outlined by the President, there are many opportunities for members to get more involved and contribute to the ongoing success of HFV. The HFV community encourages new faces to get involved in future events and activities.

Whether volunteering, joining the committee, or simply attending social gatherings, there are many ways to contribute to the growth and strength of the community.

JOIN US IN 2025!

If you missed this year's AGM, we'd love to see you next time! With so much happening in the year ahead, there are plenty of ways to connect, support one another, and make a difference. Keep an eye on upcoming events, and be part of building an even stronger, more connected community.

We look forward to seeing you there!

Happy Holidays Everyone!



NOTICES

Committee Members 2025

This month, we will be finalising our 2025 committee, and we would like to take a moment to express our sincere thanks to both the outgoing and incoming committee members.

To the current committee: your hard work, dedication, and invaluable contributions over the past year have been greatly appreciated. We are truly grateful for your commitment and leadership.

To the new committee members: thank you for stepping forward to take on these important roles. We are excited to work alongside you and look forward to all the exciting opportunities that 2025 will bring.

Thank you to everyone involved for your support and enthusiasm. We are eager to see what we can achieve together in the year ahead.

Life Membership Award

We are delighted to congratulate Zev Fishman on being awarded Life Membership in recognition of his exceptional dedication and unwavering commitment to HFV. Zev's contributions have been invaluable, and we are truly grateful for his continued support. This honour reflects the significant impact he has made, and we look forward to celebrating his ongoing involvement with us.



We're moving!

We are excited to announce that, early 2025, we will be relocating to a new office.

Please note that our address will formally change: Greenwood Park
Building 1, 301 Burwood Hwy, Burwood VIC 3125.

Should you need to visit us in person, kindly contact us via our office phone to arrange a convenient time.

Thank you for your continued support, and we look forward to welcoming you to our new location.

Office closure for the Holiday Season

Please be advised that our office will be closed for the holiday season from 20th December 2024 to 13th January 2025. During this time, we will not be available to respond to emails or calls.

We would like to take this opportunity to thank you for your continued support throughout the year and wish you a joyful and restful holiday season. We look forward to working with you in the new year!

INFORMATION

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

Committee of Management:

Dan Korn | President
Donna Field | Vice Presiden
Zev Fishman | Treasurer

General Committee:

Ben Inglis
Chris Phong
Leonie Demon
Ann Roberts
Erika Mudie
Craig Tenace

Executive Assistant:
Andrea McColl - email: andrea@hfv.org.au

Communications Officer:
Zehra Basak - email: zehra@hfv.org.au

Victorian Haemophilia Treatment Centres

Henry Ekert

Haemophilia Treatment Centre
Royal Children's Hospital, Flemington Road,
Parkville
Phone: (03) 9345 5099
Email: he.htc@rch.org.au

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

Ronald Sawers

Haemophilia Treatment Centre
The Alfred, 1st Floor, South Block
55 Commercial Road, Melbourne 3004
Phone: (03) 9076 2179 (clinic)
Phone (03) 9076 2178 (nurses)
Email: haemophilia@alfred.org.au

Professor Huyen Tran | Director of RSHC
Dr Mandy Davis | Consultant Haematologist
Dr Zane Caplan | Consultant Haematologist
Dr James McFadyen | Consultant Haematologist
Dr Caroline Dix | Consultant Haematologist
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Kara Cordiner | Haemophilia Nurse Consultant
Susan Findlay | Haemophilia Clinic
Coordinator/Administrator
Jane Portnoy | Solcial Worker
Abi Polus | Physiotherapist
Wade McGrath | Physiotherapist
Catherine Haley | Physiotherapist
Tanya Gruenewald | Psychologist

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. SUMMER 2024 cover photo: stock image George Dolgikh for Pexels.com

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: Zehra Basak



Haemophilia Foundation
Victoria acknowledges the
support of the Victorian
Government

Hello! Summer

2025 Event Dates

- New & young families catch-up: 8/2/25
- Outer Metro Dinner: 17/2/25
- HFV Family Camp: 21/3/25-23/3/25
- Youth Event: 5/4/25
- Ladies Event: 4/5/25
- Men's Retreat: 30/5/25-1/6/25
- Regional Outreach: 14/6/25-15/6/25
- School Holiday Event: 9/7/25
- Regional Outreach: 9/8/25-10/8/25
- School Holiday Event: 3/10/25
- BDAM: 25/10/25
- AGM & Christmas Picnic: 23/11/25

- Dates may be subject to change -

Further information including registration,
available on HFV website early 2025