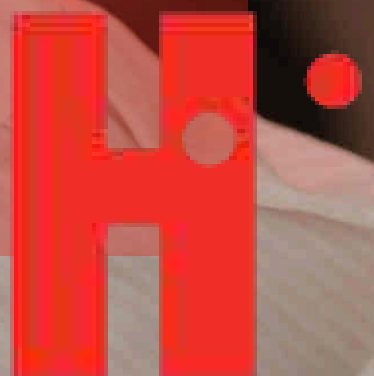


SPRING 2024

THE MISSING FACTOR

HAEMOPHILIA FOUNDATION VICTORIA



CONTENTS

03

PRESIDENT'S REPORT

04

A RETREAT FOR RESILIENCE: THE POWER OF PEER SUPPORT FOR MEN WITH HAEMOPHILIA - ZEV FISHMAN

07

REFLECTIONS OF THE PAST

08

WORLD HEPITITIS DAY

10

GROWING UP WITH GLANSMANN THROMBASTHENIA

12

ABOUT GLANSMANN THROMBASTHENIA

14

'HFV SCHOOL HOLIDAY OUTING: SEALIFE AQUARIUM

16

ASK US: BY JANE PORTNOY

17

UPCOMING EVENTS

19

KIDS CORNER

22

NOTICES & INFORMATION

President's Report

Hello everyone,

As I write this we are coming out of a week of strange weather, with gusty, blustery winds rearranging some of the treetops on my street. I hope none of you have had any major trouble due to the stormy weather. We can only hope and pray that the weather is calm and sunny for our annual Bleeding Disorders Awareness Month event on October 26th.

I'm really looking forward to seeing you all there, since it's been something of a dour winter for me (and it's nothing to do with the Tiges' woes). The walk and sausage sizzle this spring will really boost my spirits, because the HFV community has been the main group I've bonded with since coming to Australia a decade ago. When you move to a new country in your 30s, it can be challenging to make new friends. Things are different from your school years or your twenties. Your work and, if you have young ones, your children's school community are the most common places to meet new friends. But in my case I didn't have a young family, and I changed careers twice once I was here. So it's been a big help to me that the HFV community was so welcoming.

I so quickly recognised in others some of the same habits and outlook that a lifelong disorder imprinted on me I couldn't help but make fast friends. People looking on from the outside may think a genetic disorder is a strange way for it to happen, but for me at least the sense of fellowship was so strong from the very start.

All that's to say that I'm really looking forward to seeing you in person. The walk around Albert Park lake and the sausage sizzle following it are a great way to celebrate the arrival of spring weather. But even more importantly, the bonds we share as a community are worth celebrating too. For that reason, we are going to mark the 70th anniversary of HFV's founding this spring as well. Keep an eye out in the next issue for an update on how key people from our foundation's past are doing these days.

Finally, it's hard for me to believe, but our AGM is coming up too, with an event at the Werribee Zoo in mid-November just over the horizon now. Please mark your calendars as we'd certainly love to see you there. With an AGM will come a new term for our volunteer

committee, and I understand that a few people may not re-nominate. It's critically important to me that the committee have members from all across our state and representing a variety of viewpoints and experiences in the bleeding disorder community. Any of you who are considering volunteering your time for the Committee of Management, please contact Andrea at HFV office to find out more. I'd be happy to have you join us once this year as a guest; that way you can see how it goes before signing on for a full year.

That's all from me for now. I'll see you at Albert Park!

Cheers,
Dan



A Retreat for Resilience

The Power of Peer Support for Men with Haemophilia

In Melbourne, a unique annual retreat for men with haemophilia offers a vital space for connection and support. What started as a modest breakfast gathering in the 1990s has grown into a significant event, where camaraderie and shared experiences provide invaluable support to those living with this chronic condition. Organised by Haemophilia Foundation Victoria (HFV), the retreat has become a cornerstone for many in the haemophilia community.



Participants at the HFV men's retreat

The Origins

The retreat's origins trace back to the early 1990s when a group of older men with haemophilia began meeting for breakfast in Melbourne.

This initiative was driven by a need for a space where men, often reluctant to discuss their health struggles, could openly share their experiences. “We started with regular breakfasts because we wanted a place where older men with haemophilia, many of whom had severe forms of the condition, could come together,” recalls Zev Fishman. “It became clear that a more immersive experience was needed, so the retreat evolved from these breakfasts into the annual event we have today.”

A Sanctuary of Support

The primary goal of the retreat is to create a supportive environment where men can share their personal journeys with haemophilia. The schedule is flexible, allowing for organic conversations and connections. This informal approach fosters an atmosphere where participants-ranging from those in their thirties to those in their seventies-can discuss their health, share experiences, and support each other. “There’s no strict agenda,” explains Zev. “We come together and let conversations flow naturally. It’s a space where we can laugh about old stories, discuss health challenges, and support each other without any judgment.”

Navigating Life & Health

One of the retreat's most valued aspects is its role in addressing broader issues related to living with haemophilia. While clinical settings focus on treatment, the retreat provides a unique opportunity to connect and provide a safe space to discuss personal experiences, such as dealing with ageing and its impact on health.

“For many of us, this retreat is a chance to discuss topics we don't usually address elsewhere,” said Zev. “We talk about joint replacements, mobility issues, and even non-haemophilia-related health concerns. It's refreshing to have a space where these topics are welcomed and discussed openly.”



A wonderful view from The Hive at the men's retreat

Personal Growth & Connection

The retreat has had a profound impact on its attendees. Many report a renewed sense of belonging and valuable insights into managing their condition through the shared experiences and advice of their

peers. This support network often extends beyond the retreat, with participants staying connected throughout the year.

“For some, this retreat is a vital part of their life,” explained Zev. “It's not just about talking about haemophilia; it's about connecting with others who truly understand and navigating the complexities of life with a chronic condition together.”

Gratitude & Hope

As the retreat continues to evolve, HFV and participants express deep gratitude for the support and funding that have made this gathering possible. They recognise the importance of this unique space and the positive impact it has on those who attend.

“It's a place where we can be ourselves, share our stories, and support each other. I'm grateful for the opportunity to be part of something that makes such a meaningful difference,” concludes Zev. In essence, the retreat organised by HFV, is one of a number of support programs provided to members and the wider bleeding disorder community. It stands as a testament to the power of shared experiences and the strength that comes from peer support with others who truly understand the challenges of living with haemophilia. It's more than an event—it's a vital community where men find support, friendship, and hope.



WALK FOR BLEEDING DISORDERS & 70 YEARS OF HFV!



Register now:

Join Us

IN RAISING AWARENESS & CELEBRATING 70
YEARS OF HFV
| ALL ARE WELCOME |
26/10/2024 | 10.30AM - 1.00PM
COMORANT PICNIC AREA 7, LAKESIDE DRIVE,
ALBERT PARK
REGISTER NOW:
[HTTPS://WWW.TRYBOOKING.COM/CUFGP](https://www.trybooking.com/cufgp)



Reflections of the past



SHILOH RANCH - CAMP 1990

Dear Haemophilia Family,
The feeling of being part of a large family and really belonging, the caring of one to another and the sharing of experiences was something that you cannot always find. The support of people who really do know what you are talking about, as they have been there and done that.

Activities that one would not normally do, the encouragement if you were not sure if you could in fact do it.

Everything put together gives you a feeling of pride at belonging to the Great Haemophilia Family.

-Wendy Thomson



I think we all enjoyed the chance to get away from the responsibilities of home, into the outdoors. We were stimulated by the chance to try out new skills. It was great to get to each other better, to share our experiences and enjoy watching others have a good time.

-Leonie Mudge



WORLD HEPATITIS DAY

World Hepatitis Day is marked globally on 28 July. This is part of a worldwide campaign to see an end to viral hepatitis. In 2024 the national theme is It's time for action, reminding us that that hepatitis C and liver health remains an important issue for our community and that acting now is vital. This year landmarks around Australia glowed green on World Hepatitis Day to raise awareness about the campaign.

DON'T PUT IT OFF - TAKE ACTION NOW

Do you know your hep C status? Find out if you don't know.

Hep C can be cured. Treatment is simple.

Do you need liver health monitoring? Ask your doctor.

A healthy liver is vital for all of us.

**World
Hepatitis
Day** 28 July

HEP C AND BLEEDING DISORDERS

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 bloodborne 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.

WHO IS AT RISK?

It's estimated that 1 in 5 Australians do not know they have hep C.

For some people with bleeding disorders, it has been a surprise to find out they were exposed to hepatitis C, especially if they only had one or two treatments over their lifetime. This includes:

- women who carry the gene
- women and men with mild haemophilia or VWD

If you ever had a blood product before 1993, including blood transfusions and plasma-derived clotting factor concentrates, you could be at risk of hepatitis C.

Is this you or someone you know? Now is the time to talk to your doctor about a hep C test - and have treatment to be cured, if you do have hep C! Hep C tests are simple blood tests.

POST CURE LIVER HEALTH

Hep C treatments now are radically different to the early interferon treatments - a once-daily tablet, few if any side-effects and very high cure rates.

Most Australians with bleeding disorders and hep C have now been cured - but some need ongoing care of their liver health.

Were you cured of hep C? Has your liver recovered?

You might think it's all OK, but it's easy to miss symptoms of liver disease. Ignoring your liver health can have serious consequences.

If you don't know the state of your liver health when you were cured, contact your hepatitis doctor or your GP to check your liver test results. Find out if you need ongoing follow-up with a liver specialist.

REMEMBER

If you had cirrhosis or extensive scarring before being cured of hep C, you will still need to have a liver ultrasound scan every 6 months long-term.

Sadly, some people with bleeding disorders have very advanced liver disease due to long term hep C infection. Close liaison between liver specialists and Haemophilia Treatment Centres is important for treatment and care. Research into management of advanced liver disease is ongoing.

Q: Can I have gene therapy if I've had hep C?

A: Yes, as long as you have been cured or you are HCV PCR negative (no active virus in your blood) and your liver is showing signs that it is functioning normally. Talk to your doctor about this and they may refer you to a liver specialist for a liver assessment with an ultrasound, and blood tests to show that your liver is healthy.

How can you keep your liver in good shape?

A healthy liver is important to us all. Some tips from our hepatitis specialists:

1. Have a balanced diet
2. Stay active and maintain a healthy weight
3. Avoid or minimise alcohol intake
4. Take care of your mental health and wellbeing
5. Ask your doctor if you need liver health monitoring.

Find out more at www.haemophilia.org.au/healthy-liver.

PERSONAL STORIES

We are grateful to our community members for sharing their experiences with hep C. You can read their stories on the HFA website at <https://tinyurl.com/HFA-hepc-stories>.

FOR MORE INFORMATION

Visit:

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

As a Partner in the national World Hepatitis Day Campaign, HFA works with Hepatitis Australia and the state and territory Haemophilia Foundations on messages for the bleeding disorders community and is committed to making a difference on hepatitis C in Australia.

Growing up with Glanzmann thrombasthenia



Elizabeth's teenage daughter Grace has Glanzmann thrombasthenia. Elizabeth spoke with HFA about what it was like to find that your child has a very rare bleeding disorder and their family experiences as Grace grows up.

'Grace is our only daughter and has Glanzmann thrombasthenia. She has platelets in her blood but they don't function properly, so she has a treatment plan of "don't get hurt"!'

Treatment for Grace involves tranexamic acid as a starting point if she has mouth, nose, ear or face bleeds, and also for her periods. When things get more serious and she needs more help with clotting, her medication steps up to recombinant factor and she needs more help with clotting,

her medication steps up to recombinant factor VIIa (Novoseven®).

AN UNEXPECTED DIAGNOSIS

The road to diagnosis took 9 months and several referrals to specialists. As a premature baby, Grace needed regular heelprick tests when she was born. 'Her feet ended up swelling like little blood balloons,' said Elizabeth. 'Her feet ended up swelling like little blood balloons,' said Elizabeth. 'When she cried what I now know are petechiae would burst in her face, so

she would have bloom of dots on her face.’

Their GP referred her to a paediatrician, who sent her to a dermatologist at the children’s hospital. ‘The questions slowly evolved. After a bruise on her hip, they wanted to be thorough and did a biopsy so they could test from A to Z. They were explaining every disease they were testing for and made a comment, don’t worry it won’t be Glanzmann’s, it’s very rare, and then it came back as Glanzmann’s.’

‘We were first time parents and it felt like it was one long learning curve. But when she was diagnosed, it was good to know that if she cried and the petechiae happened, her face wasn’t sore or injured because the burst blood vessels didn’t physically hurt her.’

INHERITANCE - WHAT ARE THE ODDS?

When Elizabeth and her husband investigated having more children, they discovered just how astonishing it was that Grace inherited the gene alteration causing Glanzmann thrombasthenia from both of them. They are not in any way related to each other. Genetic testing confirmed they were both carriers. ‘If only one of us had given her the gene alteration for Glanzmann’s, she just would have been a carrier and we never would have known.’

It was recommended that Elizabeth and her husband use IVF to have more children, but it was too expensive to pursue after the first round was unsuccessful. ‘We’re insanely happy and proud to have our little miracle. She is an amazing human being. We tried to give her a sibling but it just didn’t work.’

MANAGING RISKS

Now that Grace is a teenager, managing her

bleeding disorder has become part of normal life. There are routines, areas that are relaxed, and some rules - ‘she needs to be safe about what she is doing.’

She participates in sport but avoids contact sports - anything where she could be hit by a bat or a ball, as well as by a person, and that includes when she is sitting out. ‘She does a lot of skill-based sport, but kids can be boisterous and she needs to make sure she is around kids who are careful. She has amazing friends now who rally around her if anything goes wrong, like if she has a bleed.’

‘Grace is a typical teenager. She loves life, she loves fishing and camping and loves being outdoors. As a parent, I try to make as many opportunities as I can for her.’ This has included working carefully with her school to make sure she can have first aid and ice any bleeds easily and quietly, ‘so she gets the most out of her classes, doesn’t feel like she is imposing on anyone or feel like she is being noticed.’

WHAT’S IMPORTANT?

‘We’ve learned to find fun things that you can do as an individual and as a family that doesn’t feel like I can only do this. When things are hard, you need something to look forward to. But things aren’t always hard!’

‘And you’re not alone. It’s just life, everyone has their ‘thing’ - it could be a nut allergy or living remotely and they deal with that in their way. And for Grace, it’s just being careful.’

*Elizabeth and Grace are not their real names

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Stock image: Emma Bauso for Pexels.com



About Glanzmann thrombasthenia

Glanzmann thrombasthenia is a very rare hereditary platelet function disorder that affects the way that platelets work in the body.

Platelets are cells in the blood that help with blood clotting. When a blood vessel is injured, platelets stick or clump together to form a 'platelet plug' at the site of the injury and to help stop the bleeding.

In Glanzmann thrombasthenia there is a deficiency of a protein on the surface of the platelet. As a result, platelets do not form a strong plug at the site of an injury, leading to a tendency to bleed for longer than normal or bruise easily.

Symptoms vary from one person to another and severity can range from mild to severe:

- Abnormal bleeding with surgery, circumcision, or dental work.
- Children experience bruising, nose bleeds and bleeding in the mouth and gums.
- Women may experience heavy or prolonged menstrual bleeding (menorrhagia), bleeding during ovulation and abnormal bleeding during or after childbirth.
- On rare occasions gastrointestinal bleeding. 1,2

The Haemophilia Treatment Centre will develop a treatment plan to manage bleeding with the person that is specific to their situation.

Glanzmann thrombasthenia is inherited in an autosomal recessive pattern. This means it occurs in the unusual situation where both parents carry the gene change causing the disorder, usually without symptoms, and each pass the gene change onto their child, who then has the disorder. It affects both males and females.³

Thanks to Dr Jane Mason,
Director, Queensland
Haemophilia Centre, for
reviewing this information.



REFERENCES

1. World Federation of Hemophilia. What are inherited platelet function disorders? WFH: Montreal, 2023. <https://www1.wfh.org/publications/files/pdf-1336.pdf>
 2. Canadian Hemophilia Society. Types of platelet function disorders. <https://www.hemophilia.ca/types-of-platelet-function-disorders/>
 3. National Organization for Rare Disorders (NORD). Glanzmann thrombasthenia. 2023. <https://rarediseases.org/rare-diseases/glanzmann-thrombasthenia/>
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HARDROCK CLIMBING

SCHOOL HOLIDAY ACTIVITY

WEDNESDAY
25/9/2024
JOIN US!



REGISTER NOW!

9.45AM-12PM

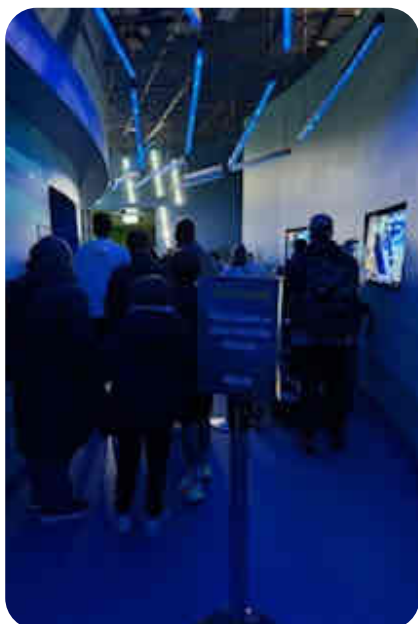
PRIMARY & SECONDARY, ALL SKILLS
WELCOME



HFV'S SCHOOL HOLIDAY OUTING SEALIFE MELBOURNE AQUARIUM

On a crisp Melbourne winter's day, HFV utilised the school holidays by organising and hosting an outing to Sealife Melbourne Aquarium. Held on the 3rd of July this special event welcomed over 40 attendees from various corners of Victoria. Thanks to the support of RCH Treatment Centre for helping promote this event to the wider community, it was wonderful welcoming 3 new families. As the aquarium's doors opened, families stepped into an underwater world of wonder, setting the stage for a memorable adventure that celebrated both marine life and community spirit.

The day kicked off with families wondering through the aquarium's stunning exhibits. The jellyfish display,



with its delicate and ethereal beauty, captivated visitors of all ages. Children gazed in awe as these mesmerising creatures floated gracefully, setting a tone of enchantment for the day ahead.

The adventure continued through to the aquarium's diverse marine life. From vibrant reef fish to the larger species, the variety on display was impressive. Children's faces lit up with excitement as they discovered their favourite fish and learned more about their underwater habitats.



One of the most thrilling aspects of the day was the series of various engaging talks and feed sessions on rays, sharks, and crocodiles. The ray feed session was

particularly captivating, with families watching as these graceful creatures glided through the water. The shark talk offered a thrilling glimpse into the lives of these powerful predators, while the crocodile session provided intriguing insights into these beautiful ancient reptiles.

Next on the agenda was a visit to the penguin enclosure. The penguins, with their playful antics and adorable waddles, delighted everyone. The informative penguin talk and feed session was a particular highlight, offering fascinating insights into the lives of these charming birds and allowing families to watch them up close.

As we look back on the day, it's clear that HFV's outing to Sealife Melbourne Aquarium was a celebration of joy, discovery, and community. With such a positive response, we eagerly look forward to continue to bring families together and create magical moments. Here's to many more adventures and opportunities for shared experiences in the future! We are happy to share that we have another upcoming school holiday outing at HardRock Climbing in Melbourne CBD on Wednesday the 25th of September. All ages and skill-sets from primary to secondary are welcome! Looking forward to seeing you and your family there.

**HardRock
Climbing - CBD
Wednesday
25/9/2024
9.45am-12pm**



Register now:
www.trybooking.com/events/landing/1270925

Stock image: Allan Mass from pexels.com



BY: JANE PORTNOY

SOCIAL WORKER

ASK US



Dear Ask Us,

What should I do when I feel that I can't manage my bills now? This is particularly challenging as I have just had to take a week off work to recover from a bleed and as I am a casual worker I am not entitled to any sick leave.

-Desperate

Thanks Desperate,

You are not alone in your struggle at the moment. With the increased costs, including rent and mortgages, groceries, utilities, and petrol, many in the community find it difficult to make ends meet. Having haemophilia certainly can increase your time off work, and impact your income. Often the unplanned aspect of these sick episodes is challenging. As a rule, trying to budget and have a "rainy day" fund is helpful.

In your current situation, make a list of your bills and debts, and your income. I recommend financial counselling. It can help you understand your financial big-picture and work out a strategy to manage the current difficulty.

The Financial Counselling Hotline is 1800 007 007, a fabulous government-funded service run by Better Places Victoria. They will be able to direct you to a local service. <https://fcvic.org.au/get-help/>

The utility companies, such as water, electricity, and gas provide a discount for Healthcare Card holders and are all deemed essential services. They are mandated to assist when you are in financial hardship. It is worth finding out what assistance you are eligible for. There are Utility Relief Grants available for unpaid bills for extreme circumstances. I have found that the telephone support line staff are helpful in this situation. Others prefer to contact by email, and this is also effective. <https://services.dffh.vic.gov.au/utility-relief-grant-scheme>

Many other forms of assistance are available, these include groceries, food vouchers, and free meals. It depends where you live, as to which services can help you out. Local councils usually have great information about local services, and Ask Izzy is a great general website, to direct people to help.

<https://askizzy.org.au/>

Of course, speaking with your friendly Haemophilia Treatment Centre social worker is a great way to find out what help is available. Phone 9076 2179 HFV can also be a support and there is an Emergency fund and a Living Well program, particularly when there is a need that relates to your bleeding disorder.



UPCOMING EVENTS 2024

School Holiday Activity
HardRock Climbing
25/9/2024

<https://www.trybooking.com/CUIBT>



Walk: Bleeding Disorders
Awareness & 70 years of HFV
27/10/2024

<https://www.trybooking.com/CUFGP>



HFV Community Christmas Picnic
at Werribee Zoo
17/11/2024

<https://www.trybooking.com/CUIDZ>



Ladies Lunch
TBC



PLEASE CUT & PLACE ON FRIDGE

ABOUT OUR UPCOMING EVENTS

REGISTRATION ESSENTIAL FOR ALL EVENTS

HardRock Climbing - School Holiday Activity 25/9/24

On Wednesday 25th of September, from 9.45am to 12pm, join us for an exciting afternoon of climbing fun at HardRock Climbing CBD. This school holiday activity promises adventure, laughter, and a chance to challenge yourself in a friendly, supportive environment.

This event is perfect for all kids, from primary through secondary school, regardless of skill level. Whether you're a seasoned climber or a curious beginner, there's something for everyone. It's a fantastic opportunity to get active, explore new skills, and enjoy some quality time with family.

It's also a great chance to connect with the HFV community, Blue-shirt youth leaders, meet other families, and chat with fellow parents. We look forward to sharing this fun-filled morning with you and making the most of the school holidays together. Don't miss out on this chance for adventure and community spirit and registration essential.

Awareness Walk: Bleeding Disorders & Celebrate 70 Years of HFV 26/10/24

Join us for a meaningful day at Albert Park on Saturday, the 26th October, as we focus on raising awareness for bleeding disorders and celebrate HFV's remarkable 70-year journey. Bring your family, friends, and colleagues for an event that combines an important cause with a chance to connect and reconnect. A wonderful opportunity to engage with the community, make new connections, and enjoy a day of activity with your loved ones.

The day starts with a walk around the lake to raise awareness for bleeding disorders. Arrive by 10:30am for an 11:00am start at Cormorant Picnic Area 7, Lakeside Drive. The scenic route, taking approximately 45-60 minutes per lap, offers a fantastic opportunity to support an important cause.

Following the walk, enjoy a delicious sausage sizzle and celebrate HFV's milestone. Feel free to bring red-themed baked goods to share and donate.

We look forward to seeing you there and sharing this special occasion! Registration essential.

Community Christmas Picnic at Werribee Zoo & Annual General Meeting (AGM) 17/11/24

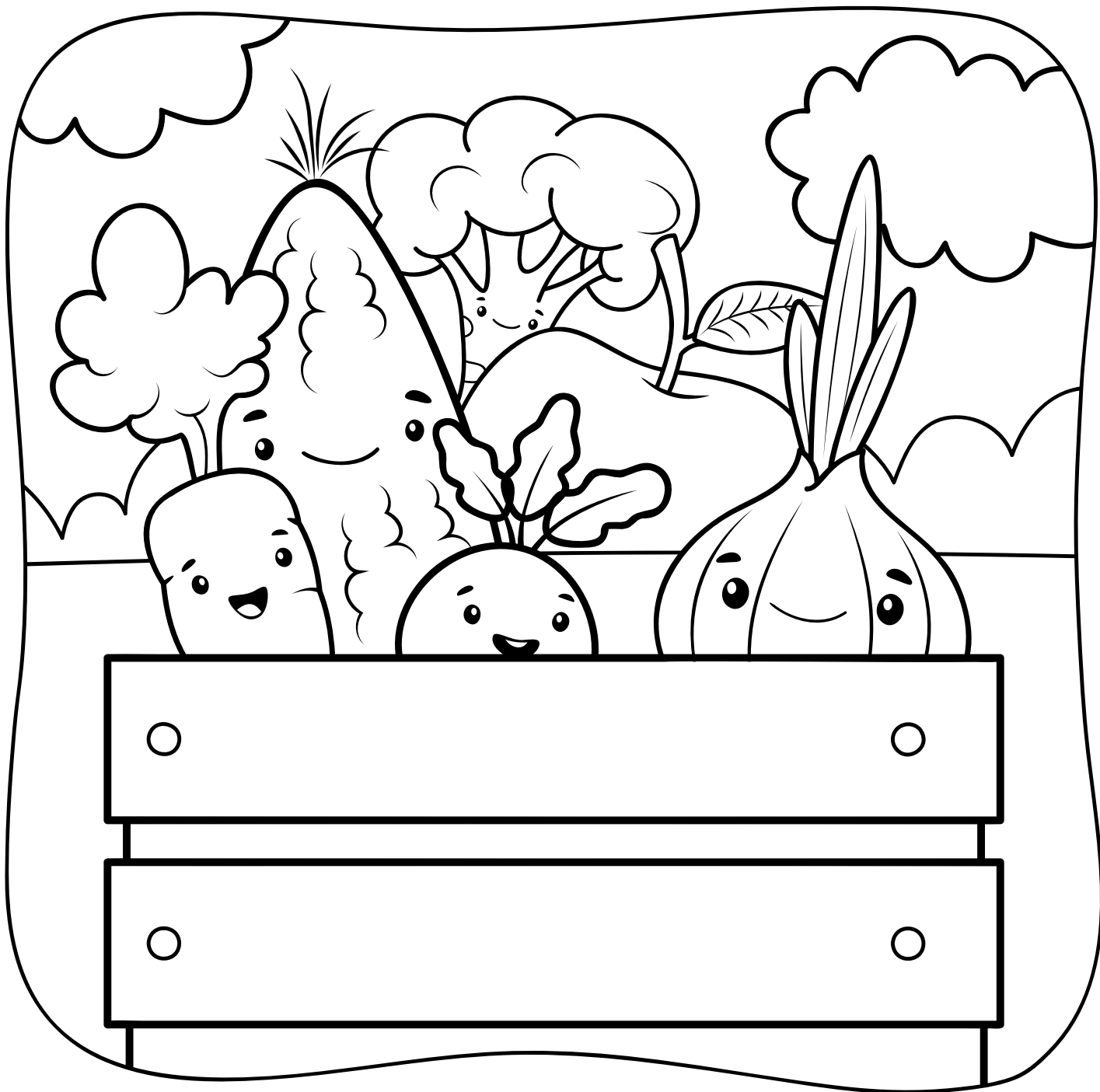
Join us on Sunday the 17th of November for a special day of the Christmas Picnic at Werribee Zoo and AGM. We recommend arriving early to enjoy the safari bus ride, as queues can be long. HFV will be stationed at Chongola Hut from 9am to 2pm. At 12pm, we hope you will be able to join us for the AGM at Chongola Hut. Where we will present our annual financial report and appoint new committee members for 2025.

Following the AGM, join us for lunch where it be a BYO picnic or utilising the bbq on the premises or alternatively, lunch from the cafe. It's a wonderful chance to relax, celebrate a fantastic year, and connect with fellow community members in the lovely setting of Werribee Zoo. You're welcome to stay till closing time. Keep an eye out for the official AGM notice, including zoom link - which will be emailed in the coming weeks and posted on our webpage. We are also seeking new committee members, those with Von Willebrand disease in particular are welcome, to support and guide the community throughout this area. For those interested in joining the committee, please find the nomination forms on our website or email: info@hfv.org.au for more information or to arrange a chat with our president/committee member.

We look forward to celebrating with you and wrapping up the year on a high note!



Kids Corner



Kids Corner



V A S A D M T I R E D C
H X L P N I R O M I N L
S A N G R G I E B S S A
H A P N E N R H H U L N
N M E P G F C Y R R T E
S S J O Y F U L L P O R
C T C G U G P I L R R V
A A H B O R E D E I T O
R R L F O S E D U S E U
E A R M L E R O T E I S
D F C O N F U S E D E N
G W O R R I E D O K E T



BORED

JOYFUL

CONFUSED

SAD

ANGRY

SCARED

SURPRISED

CALM

HAPPY

WORRIED

NERVOUS

TIRED





Lady Northcote Girls Mountain Biking Day

Are you ready to pedal your way into a new adventure? Register below at the stunning You Yangs for our Girls Mountain Biking Day—a thrilling school holiday program designed specifically for girls of all ages who are eager to dive into the world of mountain biking.

Whether you're a seasoned rider or a complete beginner, the event is perfect for you! With guidance from our expert mountain bike coaches, you'll have the chance to refine your skills or learn the basics in a fun and supportive environment.

Don't miss out on this fantastic opportunity to ride, learn, and explore. Grab your bike and gear up for an unforgettable day of mountain biking fun!

PROGRAM DETAILS:

DATES: Friday 4 October 2024

TIME: 10am - 3pm

WHERE: You Yangs (23 Branch Rd, Little River)

AGES: All Ages

COST: \$90 Per person all inclusive

INCLUSIONS: Mountain bikes, helmets, morning tea, Lunch and Afternoon tea are all provided!

SKILLS YOU WILL DEVELOP:

- **Mastering Bike Comfort:** Learn proper body position and how to tackle trails effectively.
- **Perfecting Cornering:** Develop essential cornering skills that are fundamental to all aspects of riding.
- **Gaining Bike Control:** Achieve control over your bike rather than letting it control you.
- **Descending with Confidence:** Ride downhill with assurance and enjoyment instead of just hanging on.
- **Navigating Trail Features:** Confidently handle obstacles like logs, drops, rollovers, and rock gardens.
- **Climbing Efficiently:** Enhance your climbing ability with confidence and increased power.
- **Improving Balance:** Navigate narrow, tight, and steep sections with better balance.
- **Achieving Smooth Riding:** Develop a fluid and efficient riding style for that seamless 'flow'.

The next MTB day is being held Friday 4 October, register below today to make sure your spot is reserved!

Register now: https://camps.ymca.org.au/lady-northcote-discovery-camp/programs-activities/girls-mountain-biking-day#msdynttrid=JYbGV3wCeRtIF63U4xz6LvCx3Vrav-7subkN_f0vHgk

NOTICES

Welcoming Craig Tenace!

We are delighted to announce that Craig has joined our HFV committee as a new member. His input and dedication will be a valuable asset to our team as we continue to work towards our goals. We are excited to collaborate with him and look forward to achieving great things together.



Haemophilia inheritance video

If you were born male and have haemophilia, will your children have haemophilia too?

This is a burning question for a lot of young men with haemophilia but the answer and explanation of why this occurs can be difficult to grasp.



HFA has developed a 2-minute video for teenage males with haemophilia who have questions about how haemophilia is passed on in a family. It covers:

- inheritance patterns for males with haemophilia
- a short and simple explanation of the genetics involved.

Watch the video

- on the HFA website - <https://tinyurl.com/haem-inherit-male-video>
- on the HFA YouTube channel - <https://tinyurl.com/YT-haem-male-inherit-video>

HFA is very grateful to the young people with haemophilia and their parents and the health professional experts who reviewed the video - particularly the HFV youth leaders who contributed valuable feedback and advice to its development.



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 President
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

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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

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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. Spring 2024 cover photo: stock image Andrea Piacquadio 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
Spring*

