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President's Report

Hello everyone,

This year marks HFV's 70th anniversary, and it's humbling to think of the decades of hard work that has been put in over that time by mums, dads, and people with bleeding disorder to bring us the HFV community we have today. In those 70 years, the medicines and other therapies for bleeding disorders have advanced far beyond what anyone would have thought possible in 1954. There is still much to be done though, and so I look forward to celebrating HFV with you while also strengthening it for the future to come. Members can actively support HFV by taking part in the PROBE and THOR research studies. Please find information further in the magazine.

Although our Community Camp is our flagship event each year and I love seeing whole families gather together, it's also important that we have smaller gatherings throughout the year that focus on more specific groups. This autumn we have had a Ladies' Paint and Sip event as well as a Youth Day Out. Both were well-attended and we heard lots of positive feedback from the members who were there.

We also have our Men's Retreat happening as I write this, though it wraps up too close to the publication date to feature it in this edition of our magazine. Please keep an eye out in the next issue for a report. I'm especially pleased to hear that several people who had never attended before, or who hadn't came along for many years, managed to join in this year. I'm always happy to see groups like this growing.

On that topic, the Committee of Management has also expanded from the initial members you nominated at our Annual General Meeting in December. I'd like to thank Craig Tenace for responding to our calls earlier this year for additional members. Committee has some big plans brewing for next year so if any of you are keen to be part of the it, please reach out to Andrea and ask if you can join a Committee meeting soon. We'd be happy to have you dial in as guest for one or two meetings to see what you think of it before nominating to a full appointment.

One of those plans is to run our Red Ball fundraiser again. It's been nearly seven years now since we got dressed to the nines to celebrate HFV and we think it's about time to go again.

The event couldn't have been nearly the success it was without the ingenuity and good cheer of our fundraising sub-committee. If you would like to turn your talents towards setting up a grand night for HFV in 2025, please let us know.

Overall, autumn has been an eventful few months for us. As I look at what HFV has accomplished and what we have coming up soon, I'm pretty pleased with how things stand. I hope all of you are too.

All the best, Dan Korn





HFV MEMBERSHIP RENEWAL

We need your support

On behalf of HFV President, Dan Korn, and HFV committee, we would like to take this opportunity to thank you for your support.

A reminder that your annual membership renewal falls due on 30th June each year. A fillable version of the HFV membership renewal form has been emailed and posted. The form can also be accessed via our HFV website. Simply download the form, save, fill in, re-save and email back to HFV. Only takes a few minutes of your time with simple payment options available

WHY RENEW? To take advantage of the many free and heavily subsidised HFV events and services, please make sure to be a current paid up member. HFV also need and value your support. Each and every membership strengthens HFV's voice and our ability to support and advocate for the bleeding disorders community. Even if you do not require support now, by taking out or renewing your membership, you will be helping those who do.

FEES

Fees are unchanged from previous years.

- Standard membership fee \$33.00 for individuals and families.
- Concession membership \$16.50

Families, please note:

- Family Membership \$33.00 for families includes children u18 years of age.
- HFV Youth Membership is FREE AND available for anyone aged 18-25 years and students under 30. We strongly encourage all those who turn 18 to take out their own free HFV youth membership.
- Allied family \$16.50 (grandparents, aunts/uncles, etc)

If you joined or renewed your membership recently (on or after 1 March 2024) no further action is required.

As always, please feel free to email us with any suggestions, queries or questions - info@hfv.org.au





Formation of the Haemophilia Foundation:

The History

1940's

Parents of children with Haemophilia were under enormous emotional stress. There was no effective treatment to stop bleeding. They knew there was little they could do to ease the pain and that there would be many more bleeds to endure. Patients felt helpless and frustrated watching their children enduring the painful bleeding episodes. Mothers often felt guilty about having passed on the defective gene.



1953

In 1953 there was a public appeal in the newspaper for money to support collection and production of special plasma products for a child who required an amputation to save his life. Unfortunately, the child did not survive, and there was a considerable sum of money still available. The boy's father approached Dr Sawers for advice about how the funds might best be spent. Dr Sawers recalled having seen a Haemophilia Society while in London, and suggested "The money could be used for the formation of a lay Haemophilia Society,".



1954

A public meeting was held in Melbourne on Saturday the 12th of May 1954 to discuss establishing a Haemophilia Society in Victoria. Thirty-three people attended, and were addressed by Dr Sawers. The father of the boy who died following surgery chaired the meeting, and the participants enthusiastically voted to form a Haemophilia Society. A provisional committee was elected and charged with starting the society. The Management Committee soon drew up a constitution, which was adopted on 13th of July 1954.



1955

The Committee held regular meetings for the membership. This provided forum in which parents could share experiences, ask questions, and learn from each other. Dr Sawers, asked to act as the Society medical advisor in 1955, was often called upon to give talks. The Committee agreed that Bulletins should be published quarterly. Dr Sawers was a regular contributor to the newsletter. To this day newsletters are published quarterly, as an invaluable source of information and support to members across Victoria.



1957

In July 1957 Dr Jack Morris, Director of the Victorian Red Cross Blood Bank, was appointed to the Society's Medical Advisory Panel, as a representative of the Blood Transfusion Service.



1979

Haemophilia societies in Victoria, New South Wales, and South Australia join forces, establishing the Haemophilia Foundation in Australia. This marks the start of unified national advocacy for those affected by haemophilia.



Dr Peter Schiff, Medical Director of CSL from the lates 70's up until 1999 also provided support to the society, as a medical advisor

1986

Recognising the need for legal standing, the Haemophilia Foundation becomes an incorporated association. This formalisation enhances its role as a key advocate for the haemophilia community.



1993

The Haemophilia Foundation expands across Australia, forming societies and support groups in various regions. This growth leads to the adoption of a national haemophilia logo, symbolising unity and concerted efforts for improved treatment and support nationwide.



Information sourced from The Alfred & 'Achieving the extraordinary' by Leah Lonsdale



Youth taking on the future Ben's story

In 2023 Ben Ingliss received an HFA Volunteer Award. He has been very involved in the Haemophilia Foundation Victoria (HFV) 'Blue Shirts' youth leadership program for many years and talked to HFA about his experiences and hopes for the program.



How did the Blue Shirts start?

At HFV we've been building a youth leadership team. It started off initially that we noticed we were losing people from our camp programs when they reached that teenager/young adult age. And we noticed that we weren't really giving them a space in these programs. At the camps the kids go and do the kids thing and the adults go and do the adult thing and the teenagers were in this awkward in-between space.

They weren't feeling engaged and they didn't feel like they had a place, so they weren't showing up. I was approached about this and I

had some ideas, and we put together a team with a couple of us in that age range, who love the community and love the programs, but wanted to be getting a little more out of it.

How does it work now?

Over the years the youth team has grown and expanded. Initially we would just turn up and help out but now, collaboratively as a team, we've made a code of conduct, a handbook, a set of expectations, different roles for the team, and how we want to interact in different programs. We have lots of different ideas that we're running through the HFV Committee to increase youth engagement.

What's different about it?

The really powerful thing about it is that the youth team isn't this thing that HFV is doing for the youth. We've been given a space to make something for ourselves where we can make decisions that are going to affect us, and we can have input into HFV. That's important for me and the younger members of the team, because we're going to be running this community someday.

How does it affect the future?

It gives us a chance to build our capacity and practice the sort of skills that are going to be necessary to keep the community strong and deal with the developing needs of the bleeding disorder community, which are changing so quickly these days.





How does the Youth Program grow and develop?

A major goal for me is the longevity of the program - to set up something for when I need to step down and someone else is going to step up to take that role. So, part of the planning of the team has been setting up a hierarchy.

You've got younger people who haven't really been on a program before. They're testing out if they want to be on the team and practicing and being mentored by other people.

Then we've got people who've been to a couple of programs and they know the deal. They're helping the little ones learn.

And then people higher up who are planning programs and building that documentation.

And that gradual build up will hopefully result in everyone moving up the chain within the team to the point that anyone really can take over for me if they want to.



How does it help with work skills?

We're really trying to build this to be something that members of the team can put on a resume - 'I think I'm really good for this job because I've been on this team and I've learned these skills'. A big part of leadership is getting that chance to learn and practice and realise your strengths and your weaknesses.

What's best about the youth team?

Being part of the Youth Team is also really fun and rewarding.

We're already seeing the 10-year-old kids at camp talking excitedly about hoping to get onto the team at some point. We recently had a youth camp where we had between 18 and 21 participants. it's a real testament to these guys and girls with bleeding disorders - and siblings - in the youth team. They are role models. And there's something really powerful in getting to interact with people of similar ages where you can relate to their experience. Even with kids five years younger, our experience is already so different.

It's great program and I'm really proud of what we've achieved together from it.



FIND OUT MORE

Check out other personal stories from young people with bleeding disorders on:

Factored In, the HFA youth website - www.factoredin.org.au
The HFA YouTube channel - https://tinyurl.com/HFAYouTube

Reprint and headshot of Ben supplied by HFA and reproduced with permission.



LADIES PAINT & SIP

Peer Support





ACTIVITIES AND DISCUSSIONS:

Whilst the painting provided a lot of entertainment, the discussions I had with many of the women were incredibly powerful. I was surprised by how many of us shared similar stories and experiences when learning of our son's diagnosis. Such stories have provided me with the much-needed reassurance that I am not navigating this journey alone.

Contributor: Naomi Denton

MOTIVATION FOR ATTENDANCE:

As a new member of the haemophilia Community, I felt this was a good opportunity to attend an event that would likely be more intimate and provide an opportunity to meet other women/mothers in a similar situation to me.

EXPERIENCE AND IMPRESSIONS:

From the moment I arrived at the event, I knew that this was a Community I wanted to be apart of. I felt incredibly welcomed and quickly understood that being apart of such a Community would provide me with the ongoing support I need as I learn to raise a child with haemophilia.

STANDOUT MOMENTS:

The welcoming and inclusive nature of the women, and their willingness to listen and share their experiences with me.

IMPACTFUL MOMENTS:

Similarly to the above, what resonated with me strongly, was learning that many of the women shared a similar experience to mine when their son was diagnosed. There was also a strong assurance that each of their sons is enjoying a very fulfilling life.



VALUE OF PEER SUPPORT:

That I am not alone in this journey, and that there is support when I need it.

INFLUENCE ON FUTURE SUPPORT:

Given the rare nature of Haemophilia, it can sometimes be difficult for people to understand and comprehend the emotions and reality of what it means to be raising a child with Haemophilia. The peer support available at the event confirmed for me the importance of being a part of a Community who has family members/children with haemophilia as these women understand first-hand the challenges and emotions I have and may continue to experience.

FUTURE ATTENDANCE:

Absolutely! Firstly for my own benefit, but importantly, I hope that in the future I can provide the same assistance to another young mother who has a child diagnosed with haemophilia.

OVERCOMING CHALLENGES:

Prior to attending the event, I had relied quite heavily on support from family and friends, as I was still coming to terms with our son's diagnosis. I had not yet had the opportunity to attend any events.

INCLUSIVITY AND ACCESSIBILITY:

The intimate nature of the event, for me, provided a very comfortable environment, and one where I felt incredibly included. Had the event been a lot bigger, I think I would have felt slightly intimidated to share my experiences, or chat to a larger group of people.







Voices of the Event:

HFV's Youth Day Out: Through the Eyes of Attendees

Interviewees:
Bailey Tenace & Declan Magri

On the 20th of April, the Youth Day Out event, organised by HFV, unfolded at Fortress, Melbourne, attracting participants from all over Victoria. In this interview, we delve into their personal experiences, offering a glimpse into the event's dynamic atmosphere and thier standout moments.

What did you enjoy most about the Youth Day event at Fortress Melbourne?

"The interaction with others of a similar background and the ability to feel included and welcomed," - Declan

"I enjoyed hanging out with the group and being in an environment where it's just the youth group all together," - Bailey

How did gaming contribute to making the event fun and exciting?

"It made us all interact with each other and give us all something to bond over," - Bailey

Did you meet any new friends or make new connections during the Youth Day event?

"I'd like to say that everyone I met on the day were lovely individuals and new friends,"

- Declan



Did you feel supported by your peers during the event? How so?

"Yes, because we all acted in a group and there was no negativity," - Bailey "Definitely, everyone was eager to interact and socialise creating a welcoming environment,"- Declan

How would you describe the atmosphere at Fortress Melbourne during the event?

Despite myself not having a gaming background I felt included and happy due to the character of each individual and felt the atmosphere suited the particular event,"

- Declan

Would you attend another event like this in the future? Why or why not?

"Definitely, positive past experience can only mean more to come," - Declan

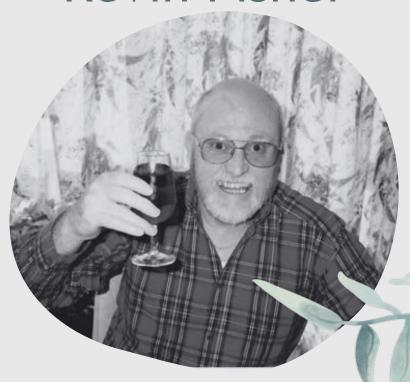
What message would you like to share with other youth about attending events like the Youth Day at Fortress Melbourne?

"It's great fun and a must do thing, everyone gets along great, u get to have amazing chats and have fun as a team," - Bailey

For more information on upcoming events, visit: https://www.hfv.org.au/events-news/events-calendar/



Kevin Fisher



Recently the Haemophilia community lost a loved stalwart, and friend to many, in Kevin Fisher.

Kevin, with his wife Judi by his side, spent countless years on committee and particularly serving as treasurer. Kevin's professional accountancy skills were meticulous and even when he had stepped down for a well deserved rest, he was always only a phone call away & ready to help out when needed.

Kevin had many challenges over his lifetime with multiple health issues alongside his haemophilia, but was always happy to greet you with a smile, talk a bit of footy and his beloved Saints, or tell you about he and Judi's latest travels, particularly his fondness for the cruises.

Kevin will be remembered as a kind, thoughtful and generous person.

Our love and thoughts go out to Judi



UK INFECTED BLOOD INQUIRY AND AUSTRALIA

The UK government Infected Blood Inquiry investigating contaminated blood and blood products released its report on 20 May 2024 after examining the evidence for 7 years. The UK government announced a financial compensation scheme to 'victims of infected blood' the following day. You can read the report at https://www.infectedbloodinguir y.org.uk/reports/inquiry-report. Some of our community members have been asking what this means for Australia.

THE AUSTRALIAN SITUATION

In Australia the initial situation with collecting blood donations and testing the blood supply was different to the UK. Australia was one of the first countries in the world to introduce hep C testing of the blood supply and had a policy of self-sufficiency in the blood supply (ie, sourcing donations from Australia only). There was an Australian Senate Inquiry into Hepatitis C and the Blood Supply in 2004, which investigated and reported on the Australian and situation Australian government Inquiry into Hepatitis C in Australia in 2015.

WHAT HAS HFA BEEN DOING?

In 2006-9 HFA undertook a hepatitis C needs assessment and described the burden of hepatitis C on our community members in our Double Whammy (2007) and Getting it Right (2009) reports. The HFA 2020 Getting Older needs assessment found that, although the greater majority of surviving people with bleeding disorders who had acquired hepatitis C have now been cured, many have financial and ongoing health, HFA support issues. has committee working on a hepatitis C strategy to address this, including the approach to HFA's advocacy, which has been ongoing for more than 20 years now.

ELIMINATING HEP C

In the HFA Double Whammy report people with bleeding disorders and hep C underlined that their highest priority was a cure.

When the new treatments became available in Australia in 2016, we focussed on reaching as many affected people as possible to promote access to treatment and a cure. We are grateful to the HTCs for their tireless efforts to review their patients and encour-

age them to have hep C treatment and be cured.

FINANCIAL SCHEMES

Although the 2004 Senate Inquiry into Hepatitis C and the Blood Supply recommended case management and financial support for health and community care costs of those who acquired hepatitis C through the blood supply, a formal program was never implemented.

Australian governments contributed to Hepatitis C Virus (HCV) litigation settlement schemes for eligible people who contracted HCV via the blood supply in Australia between 1985 and 1991, prior to the introduction of reliable screening tests for hepatitis C virus. for However, eligibility the scheme involved being able to link the individual's source of infection to a single donor with hepatitis C. HFA believes that nearly all people with bleeding disorders were excluded from eligibility as they had many treatments during this period and clotting usuallv with factor concentrates manufactured from the pooled plasma from thousands of donations and they could not

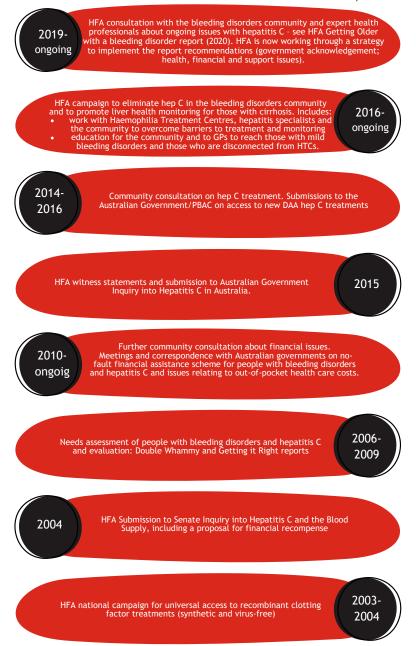
identify a particular treatment batch or a single donor. Apart from a small ex-gratia payment that was made by the ACT people government to with bleeding disorders who acquired hepatitis C through the blood supply, there have been no other government financial recompense schemes for people with bleeding disorders in Australia. HFA has been active over many years in hep C advocacy.

Some key activities are below. For a full list of HFA activities and links to the documents, visit the HFA hepatitis C strategy page on our website: https://tinyurl.com/hfa-hepc-strategy.

The HFA Getting Older report highlighted that hepatitis C leaves an ongoing legacy for many in our community. We continue to work on a strategy to implement the report recommendations and will

advise of any further steps and outcomes.

We are aware that revisiting these issues can be painful for some members of our community. We encourage you to reach out for support if this experience is challenging for you - eg, State, Haemophilia treatment centres social worker/psychologist or your preferred counsellor. You may also wish to seek a counsellor through your GP or contact a service like Lifeline (call 13 11 14).



BY: JANE PORTNOY

ASK US



What was the standout moment for you at the World Federation of Haemophilia conference in Madrid, and how did it change your perspective on managing bleeding disorders?

I've just returned from the World Federation of Haemophilia conference in Madrid.

What an amazing experience to go to an international conference, with people from all over the world. I enjoyed the mixture of people with bleeding disorders, their families, the health care professionals, doctors, nurses, physios, social workers, psychologists, researchers, scientists, and also the advocates from the associations of haemophilia, and NGOs from around the world.

As I sat in the audience I felt connected to such a diverse group by a shared interest in haemophilia and bleeding disorders. Later walking around the poster display and talking with attendees' conversations were stimulating, and often surprising.

There was amazement when one of my colleagues asked how to help patients remember to take their prophylaxis. The answer from another audience member was to tell them about "us", we don't have access in our country and then they will understand that they need to take their treatment.



WORLD HEPATITIS DAY 2024

In July 2024 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 28 July

On World Hepatitis Day the international community comes together to step up efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. In 2024 the national theme is It's time for action.

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

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

Good liver health is a hot topic for everyone in the bleeding disorders community - and in gene therapy good liver health is a requirement. We will be looking at strategies to manage your liver health as part of our World Hepatitis Day activities. On World Hepatitis Day we are reminded to take action - know your hep C status, have treatment to cure hep C, where possible, and follow up on your liver health after treatment.

By talking to our friends, family or a doctor about testing, treatment, liver health checks and managing liver health we can work towards these goals.

It's also important to be aware that sadly, some people with bleeding disorders and hep C have advanced liver disease caused by long term infection. Close liaison between liver specialists and Haemophilia Treatment Centres is key to care and treatment. Research into management of advanced liver disease is ongoing.

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





Research opportunity

<u>The Haemophilia Osteoporosis Registry(THOR)</u> is a research study looking into bone and joint health in men with haemophilia A. Participants will undergo a free comprehensive musculoskeletal health assessment at Monash Medical Centre upon entry into the study and again after 12 months.

The THOR team is currently looking for males 18 years and older with moderate to severe haemophilia A. If eligible to partake in the study, you will undergo a series of health assessments. Some of these assessments include a bone density scan, muscle strength testing and a high-resolution 3D bone scan. This is a joint study between Monash University, Monash Health and The Alfred HTC.

Interested or have more questions? Visit the THOR website for more information - https://www.thorstudy.com/



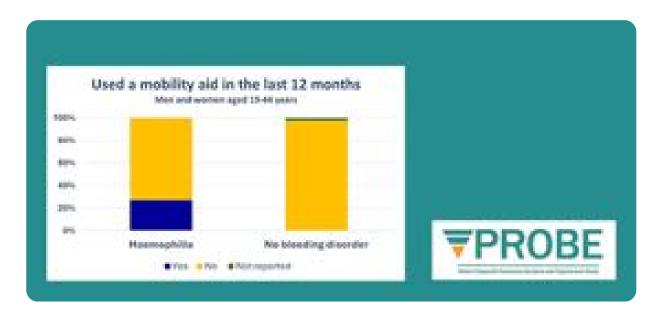


HAVE YOU DONE THE PROBE SURVEY YET?

What difference have new treatments made to the experience of haemophilia in Australia?

The PROBE Australia Study helps HFA collect the evidence to advocate for new haemophilia treatments. And you can contribute to that evidence.

You can see from our 2020 PROBE study results how many people with haemophilia experienced chronic pain back then - nearly 70% of men and women aged 19-44 years, compared to around 30% of people without a bleeding disorder in the same age group.



Please consider completing the PROBE survey and tell us what your experience is now.

We currently have about 250 responses. For strong results we need about 150 more men and women to complete the survey.

Who can take part?

- · Men and women with haemophilia or who carry the gene
- AND men and women without a bleeding disorder, like family and friends, health professionals, and other people interested in haemophilia

Participate in the PROBE Australia Study today and contribute to our real-world evidence on haemophilia!

Find out more at www.haemophilia.org.au/probe-australia-study.



HIGHLIGHTS FROM MOVIE



























NOTICES

HFV Committee Check-ins

Our dedicated HFV Committee members are preparing to touch base with our cherished general members! Expect a friendly phone call soon for feedback, check-ins, and more -your voice matters!

Membership Renewal:

Calling all members! It's that time of the year again. Membership renewal is now live. Don't miss out on the exciting opportunities and benefits awaiting you within our vibrant HFV community.

WHY RENEW? Take advantage of the many free and heavily subsidised HFV event and services - please make sure to be a current paid member. Each and every membership strengthens HFV's voice and our ability to support and advocate for the bleeding disorders community. Even if you do not require support, by renewing your membership, you will be helping those who do.

Renew today and stay connected!

HFV's 70th Birthday:

Get ready to celebrate! This June marks a monumental milestone as HFV turns 70! An event is in the works - be sure to keep an eye out on emails, website and our socials for the birthday date. Let's make this celebration one to remember!



INFORMATION

Haemophilia Foundation Victoria

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

info@hfv.org.au www.hfv.org.au

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

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President: Dan Korn

Vice President: Donna Field Treasurer: Zev Fishman

GENERAL COMMITTEE:Ben Inglis | Chris Phong | Leonie Demon |

Ann Roberts | Erika Mudie

Victorian Haemophilia Treatment **Centres**

Henry Ekert

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Phone: (03) 9345 5099 Email: he.htc@rch.org.au

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Susan Findlay | Secretary
Jane Portnoy | Haemophilia Social Worker
Abi Polus | Physiotherapist
Wado McCrath | Physiotherapist Wade McGrath | Physiotherapist Catherine Haley | Physiotherapist Natalie Evans | Data Manager

Membership Annual Fees:

\$33.00 Standard family membership \$16.50 Concession / Allied (Youth Free) \$55.00 Organisational member

* No joining fee for new members joining at the Standard Family Membership rate.

Ambulance Subscription Subsidy:

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee. (Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:

Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

MedicAlerts

MedicAlerts: A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to \$30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

Live Well Funding:

Live Well Funding is open to all current financial members who can apply for funding for any activity or one off item that will assist in the management of their conditions such as mobility support aids, meditation, massage etc.

Care and Counselling:

This is available through your treatment centre.

Magazine:

Your quarterly magazine offers information and details of upcoming events.

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



