

SUMMER 2022

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THE MISSING FACTOR

connect • support • empower

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Speed Boat Circuit Racing • Ask Us
New Haemophilia Therapies
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HFV is committed to Child Safety. Our Child Safety Statement is available for review on our website www.hfv.org.au

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

Opinions expressed in The Missing Factor do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres. The content of this publication is provided for information purposes only. All information is provided in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. No claim is made as to the accuracy or currency of the content at any time. HFV do not accept any liability to any person for the information which is provided.

HFV is funded through the Department of Health and Human Services under Blood Borne Virus Sector due to the historical impact of contaminated blood products on the haemophilia community.

HFV supports our diverse community and our magazine reflect topics that impact our community including bleeding disorders, BBVs, mental health and positive health promotion.

Editor: Yarrow Ruane



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

PRESIDENT'S REPORT

Hi HFV family,

Christmas has arrived again and it is time to celebrate with family and friends. As we wind down for 2022, it is a great time to reflect on a job well done at HFV. It has been a bumper year and has been fabulous to reconnect with many of our members again in person. Although COVID remains an ongoing concern, we have really enjoyed the scattered opportunities in 2022 to see familiar faces and meet with new families. Events included the camp, walk around Albert Lake and a regional visit, just some to name a few.

And 2023 is shaping up to be even bigger! We have planned our calendar and there is something for everyone. Events start on 4th Feb with a delayed AGM at Zone Bowling Moorabbin. Join us in some friendly competition amongst the committee and HFV members, followed by such culinary delights as hotdogs and chips! Please add it into your events for 2023.

Many other events will be coming so please stay tuned and mark events into your calendar so you don't miss out. The national conference is in March. As it is in Melbourne, HFV will be hosting some activities. We are hoping to connect with our valued members as well as with our counter parts from other states. We would love to see you there and if you would like some financial assistance to attend, please contact the office to chat to Yarrow or Andrea. The conference is full of information and it is a time to share our experiences and support others in our community that may be doing it tough. Please add the dates into your plans for 2023 and really hope to see you there.

However, 2022 still has one more gift to give you....our newsletter! Another bumper year with so

many articles and insights to share. Are you interested in boat racing? Read our article from Drew Reid about his interesting journey (p.4). More information on Hep C (p.13), including a personal story. We are reminded as well of the importance of our liver health so again, a valuable article to consider. Yarrow is also sharing some reflections from those living with HIV (p.17). Gene therapy will always hold our interest as we dare to dream about what could be for many in our community. Please take time to read the article on New Haemophilia Therapies (p.8) to build our knowledge to prepare for the future we all hope to share.

As we get ready to close the office doors in the next week I do want to take this time to thank all that support HFV.

The committee that all work so hard and cohesively in the background. Many thanks for all that you do. I have the privilege of being out front at events but each and every one of the committee fulfil a very important role. We cannot do the work without you.

The staff! What can I say. Yarrow has celebrated his first anniversary with HFV and very much feels as if he has been here for years. Yarrow has really strengthened our newsletter after filling the enormous shoes left by Julia. Yarrow has not only done this without missing a beat but has joined our community with dedication to our shared cause, very much embedding himself into our community. Many thanks Yarrow. Andrea has yet again completed a year of amazing dedication. It has been a very tough year for Andrea and we are so grateful for her ability to continually put others ahead of her own needs. Andrea will always welcome everyone with open arms and always puts the best for HFV ahead of her own needs. We are truly blessed with an amazing team of staff and I want to thank them very sincerely for all

they do especially in what has been very challenging times.

For those in our community that attend our events, we thank you. Our work is all about you! The many hours provided by our volunteers demonstrates the dedication shared at HFV to connect, support and empower. Our mission is simple - everything we do is to provide opportunities for our communities to learn a bit more about their health outcomes, become more empowered, connect with others impacted by similar life challenges and share our stories to support each other. We hope to continue to bring people living with a bleeding disorder together, to strengthen all of our experiences.

We need you to continue the work. Our committee is too small for all the work to be done. So if you have a few hours a month to join us please let us know. We are all happy to explain what is required and each and every member has something very valuable to offer - your time, your passion and your life experience. We hope to hear from you. The AGM is the perfect time to join, so this is a personal call out to you (yes YOU)! Make 2023 your year of action - come join the HFV team!

Have a very happy and safe festive season. I hope there is time in your life to enjoy the company of your loved ones, celebrate a year of love and good fortune, and bring in 2023 surrounded by those that care for you. Good health and happiness and look forward to seeing you in 2023!



Leonie Demos

HFV President

Speed Demon Drew on Circuit Racing

Andrew Reid

When HFV set out on our Gippsland regional visit earlier this year, we never expected that to meet a National Champion boat racer! Drew tells us all about how he got into racing.

My name is Andrew (Drew) Reid. I live in Traralgon in country Victoria – about two hours South-East of Melbourne. I have haemophilia B. I was diagnosed at around 10 months old, stemming from a tongue bleed that would not stop.

How did you first get into racing?

My parents had been spectators at racing events since before I was born, so my brother (who also has haemophilia B) and I have been going since before we can remember. We also had a couple of different Ski boats growing up. When I was around 19 years old, I took our ski boat to the local club to help out during a race day. This led us to meet racing people and start to forge some friendships that we still have today. My first true experience was the first time Dad taught me to drive our Chevy powered ski boat... Guess I kind of awoke the speed demon!

What are the different types of motorboat racing?

We are involved in Circuit racing (like Speedway, Oval track) but there is also Jet Sprint, Drag (1/4 mile) and Offshore (out in the ocean). Most of the courses we race on are Oval shaped. The size and shape depend on the venue but lake courses are usually wider than the more narrow river courses. There is a lot of difference between the types of boats. To start with,



“My first true experience was the first time dad taught me to drive our Chevy powered ski boat... Guess I kind of awoke the speed demon!”

there are different engine formats. For Inboards, modified car engines are mounted inside the hull. For Outboards, the engine is mounted on the back of the hull like on a normal fishing boat. KT is a mix of both, where the engine is mounted inside the hull and a drive unit mounted on the back of the hull. There is a range of different hull designs from displacements, hydroplanes, tunnels, and monos. You can find more info at: <http://www.ausapba.com.au>.

What made you choose the type of racing you would do?

Being spectators following circuit boats growing up, that was really the only option. Circuit racing ticked the right box – hence why we travelled to watch race meetings. The class of boats we have raced came from the opportunities we had to test drive different boats. My father and brother have raced in Displacements, with myself racing both Displacements and Hydroplanes.

What is it that keeps you interested?

Firstly, the friendships. Catching up with our racing family is a big part of the enjoyment at a race meeting. Secondly, the racing itself. It tingles the whole body – you experience everything from nerves to adrenaline to pure excitement.

Do you feel like motorboat racing has changed your relationship to haemophilia?

I would not say it has changed anything to do with my haemophilia. The sport is partly about taking a calculated risk and the dangers involved so safety is very important for everybody involved in the sport, no matter who you are.

Has your haemophilia caused any problems with racing?

At this stage it has not caused

any problems at all. There is always family around to assist with information for safety crews should something happen. I also always travel with a treatment kit, should it be needed. Years ago, when my brother and I started getting our race licence, there was no question on the forms about bleeding conditions. The modern forms now have that question but it has never led to our licence application being rejected.

Do you have any memorable moments?

In the 2001-2002 season, I won the National Championship in the 1.6 litre Hydroplane class, finished on the podium for the Australian Championship, and also finished on the podium for other trophies over the season. That was my best individual season. As a team, I have assisted

my father in winning nine Australian Championships as his Crew Chief.

How can the community stay up-to-date with results?

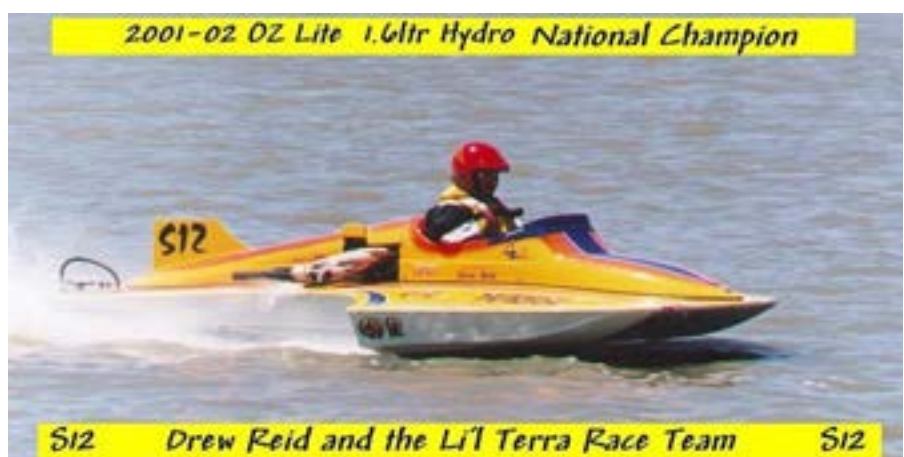
There is a calendar showing dates and venues Australia-wide at: <http://www.ausapba.com.au>

What is one thing you would say to someone thinking about taking up the sport?

Go for it! Even if you don't want to race a boat but you are into engines or just want to be involved as a helper to a team or a club. You don't need superhuman abilities or be built like an AFL player, and you won't be the only one with a limp or a funny arm in the pit area. There are all kinds of people from all forms of life involved in the sport and that is part of what makes it so enjoyable.



L-R, Drew's dad Bob, Drew's youngest daughter Elsie and Drew with the State Championship Trophy for their class.



Ask Us: Psychosocial Disability and the NDIS

By Lilly Donnelly

Dear Ask Us,

What is a psychosocial disability and am I eligible for the NDIS?

Hey there,

The National Disability Insurance Scheme (NDIS) can be confusing and hard to navigate. Guided with the right knowledge and support, however, the NDIS can benefit individuals who require support and funding. Hopefully, this brief summary can help answer some common queries.

The NDIS only provides funding or supports for chronic health conditions that are related to a person's disability. This means that having a bleeding disorder alone does not make you eligible for NDIS funding. However, you may be eligible based on other conditions that you have, which might be related to your bleeding disorder.

You may be eligible for NDIS if your bleeding disorder is having a severe impact on your life and/or affects your ability to perform daily activities...

...This includes psychosocial disabilities (disabilities that might arise from mental illness like anxiety or depression) and/or physical health conditions (like joint pain that limits your mobility).

It is important to note that the NDIS does not fund therapy to address symptoms of mental illness. Rather,

the NDIS funds ongoing functional support for daily living. This support could include assistance in getting to medical appointments, finding a suitable house, searching for a job, helping to prepare meals, and psychosocial training/coaching to learn skills to help improve the situation.



Not Sure if You're Eligible?

If you are not sure whether you have a psychosocial (or other) disability, it is a good idea to think about whether any of your daily activities are impaired or restricted by your physical and/or mental health.

SOME QUESTIONS TO ASK YOURSELF:

- Do you have the stamina to complete daily tasks (mentally and/or physically)?
- Do you have restricted mobility due to joint pain?
- Are you able to cope with time pressures and multiple tasks?
- How do you go interacting with others?
- Are you able to manage stress?

If you have further questions about the NDIS, getting in contact with your local GP or Haemophilia Treatment Centre Social Worker for further support is always a good idea.

Contact NDIS:

W: [ndis.gov.au](https://www.ndis.gov.au)
T: 1800 800 110
H: Mon-Fri
8am-5pm



Lilly Donnelly is a La Trobe University social work student. This article was written for "The Missing Factor," 2022, during Lilly's placement at the Ronald Sawers Haemophilia Centre at Alfred Health.



New Haemophilia Therapies

Adapted from:
New therapies
HFA Zoom and Facebook Live webinar,
13 October 2022

It is an exciting time with more new haemophilia treatments likely to become available in Australia, but there have been a lot of questions about them and what they will mean for treatment and care. How do they work? What difference will they make for people with haemophilia? How will they impact on comprehensive care?

In the New therapies webinar for Bleeding Disorders Awareness Month, Dr Liane Khoo and Dr Sally Campbell gave simple and clear presentations explaining the new extended half-life (EHL), non-factor therapies and gene therapies for haemophilia and were joined by haemophilia nurse Stephen Matthews for a Q&A to answer audience questions.

NEWER HAEMOPHILIA THERAPIES

Understanding the way haemophilia treatments work can be challenging and Dr Liane Khoo's presentation on newer haemophilia therapies was a very user-friendly explanation of the sophisticated technologies involved.

She explained that the

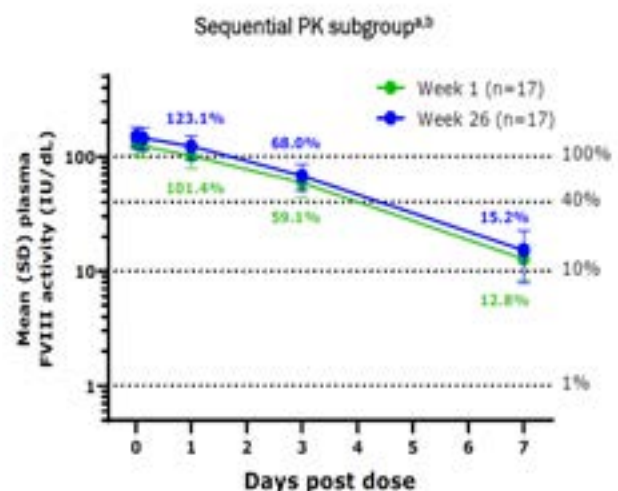
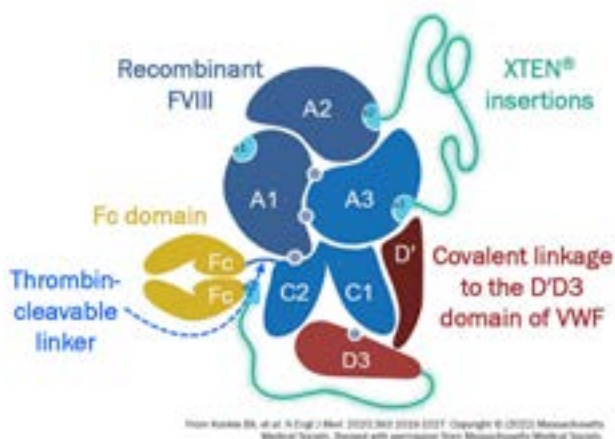
definition of prophylaxis has changed in recent years. It now covers 'the administration of agents' - it is no longer limited to infusing clotting factors into a vein but can be a range of therapies given in a variety of ways. The goal of prophylaxis is also more ambitious - aiming to prevent bleeding, allowing people with haemophilia 'to lead active lives and achieve compara-

ble quality of life' to people who do not have haemophilia.

Extended half-life factors (EHLs)

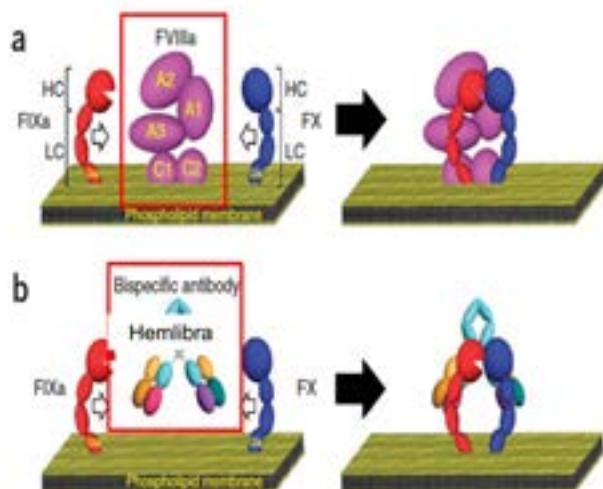
Adding the sugar molecule PEG (polyethelene glycol) to haemophilia replacement factor therapies has meant that their half-life can be extended, ie, how long it takes the active substance in factor

Even Newer Technologies for half-life extension (Trial)



Non-Factor Replacement Therapies : Current

Monoclonal Antibodies



Kilgus et al. 2012; Nature Medicine, 18(10): 1570-4.

- Restores the function of missing FVIII
- Haemophilia A patient **WITH** and Without inhibitors
- Steady state level



- **Subcutaneous**



to reduce by half in the body. As a result, the factor lasts longer in the body and fewer injections are needed.

Other ways of making the factor last longer in the body have been by attaching other types of molecules to it, such as fusion proteins. There are now also clinical trials of even newer technologies to extend the half-life of factor, with good results.

Non-factor replacement therapies

Liane Khoo explained that monoclonal antibodies like Hemlibra® (emicizumab) do the same job as factor VIII (8) by helping the body to form a clot. However, these treatments work a bit differently to replacement factor therapy:

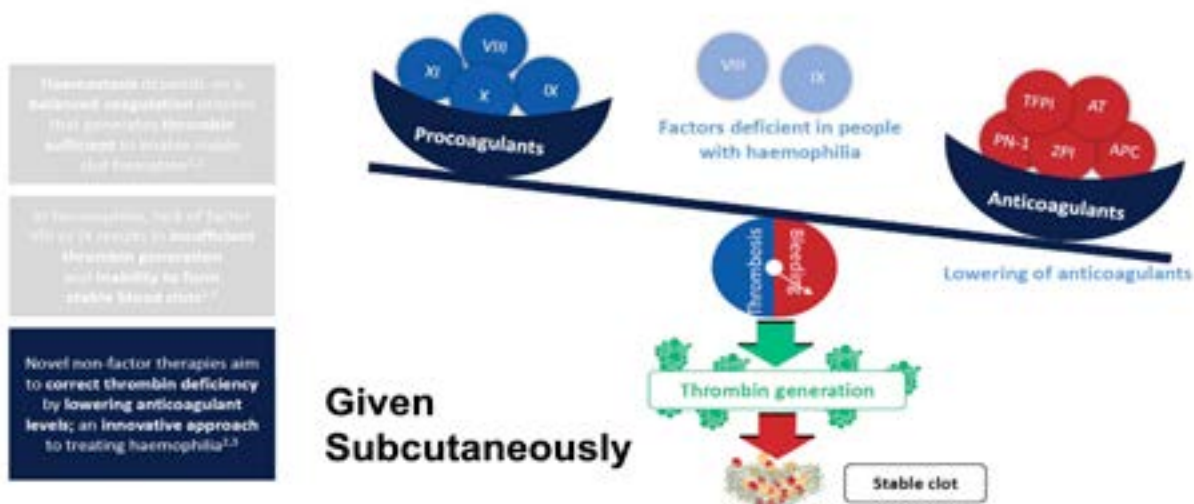
- They can be injected un-

der the skin.

- They can be given to patients with and without inhibitors.
- They maintain a constant steady level in the body.

She also touched on re-balancing therapies that are currently in clinical trial. These therapies are different again. They work by lowering anticoagulants to balance the deficiencies in clotting

Non-Factor Replacement Therapies (Trial) → Re-Balancing Therapies



APC, activated protein C; AT, antithrombin; FVIII, prothrombin; FIX, factor IX; FXI, tissue factor protein inhibitor; ZPI, 2 dependent protease inhibitor; S, Wilgus, C. Nature, 2014, 513(7538): 6-7; Regner, C. et al. Blood Rev, 2015, 29(2): 100-105; S, Sogami K and Shima M. Blood, 2015, 125: 299-305. Figure adapted from Rymaszewski K, et al. Thromb Haemostasis 2020

New Comprehensive Care



factors VIII (8) or IX (9) that cause haemophilia.

New comprehensive care

What do these new therapies mean for comprehensive care? She looked at the situation when the patient and their family is at the centre of care and the multiple services that would need to be available across Australia, no matter

where you live, to achieve the goals of care.

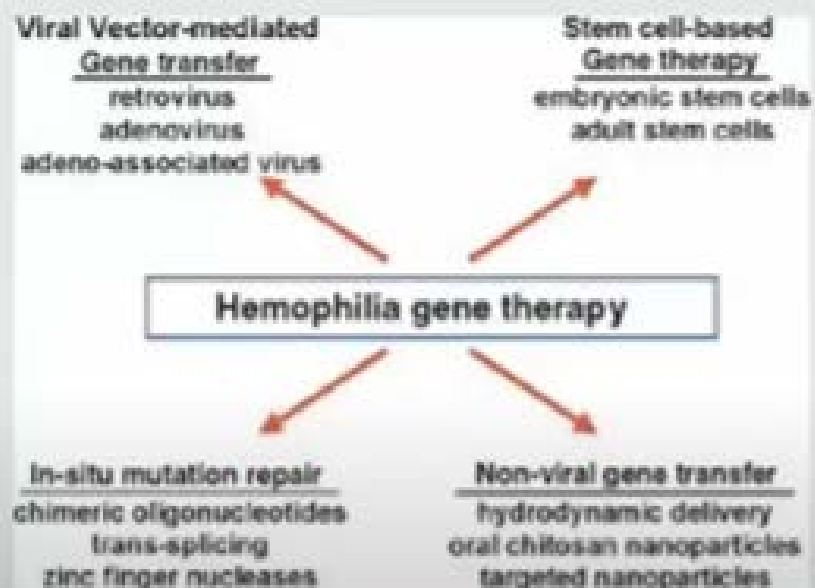
GENE THERAPY

Dr Sally Campbell introduced her presentation with a list of the haemophilia treatments currently available in Australia and commented that with individualized treatment, each person with haemophilia would need a

treatment that is right for them - and that what is right for one person may not be for another.

She focused on gene therapy for haemophilia. Viral vector-mediated gene transfer is now in advanced clinical trials, but three other approaches to gene therapy are also being explored: stem cell-based gene therapy

Gene therapy



apy, in-situ mutation repair and non-viral gene transfer (see bottom slide p.10). She explained briefly how the different types of gene therapy work and, in particular, the viral vector-mediated gene transfer method in haemophilia.

She explained that the medicines review processes have just commenced for haemophilia gene therapies in Australia and that they will take some time before gene

therapies are available to patients. Patient considerations for gene therapy will include:

- Eligibility - what are the criteria for who can have gene therapy
- Durability - how long the effect of the treatment will last
- Factor level - what factor level will result
- Genotoxicity - could it cause an adverse event, eg cancer.

It will be important to discuss these questions with your Haemophilia Treatment Centre team, but liver health will be a key issue, as all of the current AAV gene therapies target the liver. She pointed out that what would be classified as a 'success' with gene therapy would be very individual and depend on what you wanted to achieve with the treatment.

Gene Therapy Q&A

Stephen Matthews and Sharon Caris joined Liane Khoo and Sally Campbell to answer questions from the audience.

What would gene therapy for haemophilia involve for a patient?

- Think of gene therapy as just another treatment. It may change you from severe haemophilia to mild haemophilia, but you can still pass haemophilia onto your children.
- Currently only adults can access the therapy
- You need to make some significant commitments, for example:
 - at least 6 months of weekly visits to your HTC for monitoring
 - a year of abstaining from alcohol.

If I have had hep C and been cured, can I have gene therapy?

- Yes, if your liver is showing signs that it is functioning normally.

What are the timeframes for access to gene therapy in Australia?

- Gene therapy needs to go through several government assessment processes to see if it can meet the requirements to be a government-funded treatment in Australia
- There also needs to be discussion about how it would be funded in Australia
- This may take a considerable time
- There would need to be some advocacy from HFA as part of this process

What can I do to prepare myself for gene therapy?

- Work towards a healthy liver, with a moderated alcohol intake, weight management, being as active as you are able to be and avoiding medications that are toxic to the liver, where possible.
- Take care of your mental health, as you may need steroids with gene therapy and these can affect your mood.

The “New Therapies” Bleeding Disorders Awareness Month webinar discussion also highlighted that people can consider new therapies and see some benefits even if they are older and have damaged joints.

This was a lively and informative webinar - many thanks to the speakers for putting it together.

Want to find out more about new haemophilia therapies?

- Watch the webinar at:
<https://tinyurl.com/HFA-new-therapies-webinar>
- Read the HFA gene therapy information:
<https://tinyurl.com/HFA-gene-therapy>



Facilitator:

Natashia Coco, Haemophilia Foundation Australia

Speakers:

*Dr Liane Khoo, haematologist & Director
Haemophilia Treatment Centre
Royal Prince Alfred Hospital, Sydney*

*Dr Sally Campbell, haematologist & Acting Director
Queensland Haemophilia Centre
Royal Brisbane & Women's Hospital*

*Stephen Matthews, Clinical Nurse Consultant
Haemophilia Treatment Centre
Royal Prince Alfred Hospital, Sydney*

Sharon Caris, HFA Executive Director

Watch the webinar online:

<https://tinyurl.com/HFA-new-therapies-webinar>

TURNING LIVER HEALTH AROUND AFTER HEP C

JAKE'S STORY*



**Jake is not his real name*

'Now that my liver is working better, everything is better.'

For Jake, managing hepatitis C and taking care of his liver health has been a long journey, but every step has been worthwhile.

Jake has mild haemophilia B. He first found out he had hep C as a young boy in the 1980s when the children's hospital called him in for testing. At the time he was more worried that he might have HIV, as that was a big concern for people with haemophilia.

'It was a strange time. When they told me and my parents that I had non-A non-B hepatitis - that's what hep C was called then - the nurses were all gowned up and wearing gloves and masks. I had never seen it before. It was a bit like COVID.'

LIVER HEALTH PROBLEMS

After his diagnosis Jake was monitored regularly with liver function tests. His doctors explained that hep C might progress slowly and they would need to keep an eye on his liver health.

'For quite a few years there was little change and I didn't think much about it. Then in my mid-20s the doctors could see some small differences in my liver function tests. I had a transjugular liver biopsy and that showed a little bit of damage in my liver.'

But suddenly in his early 30s his liver health started deteriorating and at a rapid rate. This was some years before 2016, when the new highly successful DAA hep C therapies became available in Australia. He commenced triple therapy treatment with telaprevir, interferon and



ribavirin but did not respond to treatment.

‘That was really disappointing and I was very upset. The next year I had another biopsy and they told me that I had definitely developed cirrhosis. Things got really bad for me then. I felt horrible, tired and very anxious.’

HEP C CURE

With a combination of non-response to treatment and haemophilia, his options for clinical trials in Australia were very limited at the time. Desperate, he applied for clinical trials around the world and just as he was losing hope, he had a positive reply from a clinic in the USA. This was no ordinary situation. He persuaded the clinic he could take responsibility for himself and his health, his hospital in Australia provided all his clinical

documentation, then he travelled to and from the USA to participate in the trial.

His hep C treatment was Harvoni® (ledipasvir and sofosbuvir), one of the DAA therapies that are now widely available in Australia.

‘I had one tablet a day for 12 weeks. Side effects? Some confusion and blurry vision, but my liver was in pretty bad shape so it might have been something else. And it all returned to normal as soon as I finished treatment. It was a piece of cake compared to interferon.’

When he received his results showing he had been cured of hep C, Jake was not surprised.

‘I already knew. I felt different. I felt good’

CIRRHOSIS MONITORING

Even though his hep C has been cured, Jake had cirrhosis before treatment, which means he needs ongoing liver health monitoring.

‘I have to have 6-monthly liver checkups because with cirrhosis I’m at an increased risk of cancer. I go to a liver clinic at the hospital to see a specialist - the same hospital as my Haemophilia Treatment Centre, just in case there are any issues with my haemophilia.’

Jake sees this as part of his routine care. He has some tests and an ultrasound then follows up with an appointment with the specialist about a week later to discuss the results. With COVID, his specialist appointment is now via telehealth.

‘It’s no big deal. As we get

older, we need to be more careful of our body anyway. The liver function tests are normal blood tests - I just have them every 6 months, along with other regular blood tests I have, like cholesterol and blood sugar. And I can do them at the pathology unit at the weekend if I want to. The ultrasounds are at the hospital. They are painless, take 5 minutes. And the hospital will do their best to work around your schedule.'

While it can involve time off work, Jake thought the effort was well worth it.

'I don't think anyone likes to have health checks all the time, but it is definitely peace of mind. If they find something, they can act on it straight away. You don't want to find out down the track when there is not much you can do.'

LIVER HEALTH AND WELLBEING

Since his hep C cure, Jake's liver health has improved remarkably.

'I still have a bit of liver damage now, but it is not nearly as bad as before treatment. It's amazing.'

'Now that my liver is working better, everything is better. I have as much energy as when I was 21 years old. My moods are better. I don't get itchy, I don't get brain fog, I feel fine after a big meal.'

Jake has made changes to his lifestyle to take care of his health generally and thinks this has made a difference to his liver health recovery.

'I do help my body a lot. I haven't drunk alcohol in 14 years. I don't smoke. I walk a lot. I eat a Mediterranean

diet and don't eat much red meat or sugar.

His message to others?

'We are living in different times. Anyone thinking about hep C treatment, just do it. Don't hesitate. No one should live with hep C, especially these days. Treatment has never been easier.'

'The damage to my liver happened so quickly. For years there was no change, then suddenly it went from bad to much worse.'

'Make the effort to have treatment and follow up on your cirrhosis. Don't give up. Life's too short to take chances.'

Article printed with permission from Haemophilia Foundation Australia.



World AIDS Day 2022

World AIDS Day is marked globally on 1 December. In 2022 the national theme for World AIDS Day is Boldly Positive.

World AIDS Day aims to encourage Australians:

- to educate themselves and others about HIV
- to take action to reduce the transmission of HIV by promoting prevention strategies
- and to ensure that people living with HIV can participate fully in the life of the community, free from stigma and discrimination.

On World AIDS Day you can show your support for people with HIV by wearing a red ribbon, the international symbol of HIV awareness and support.

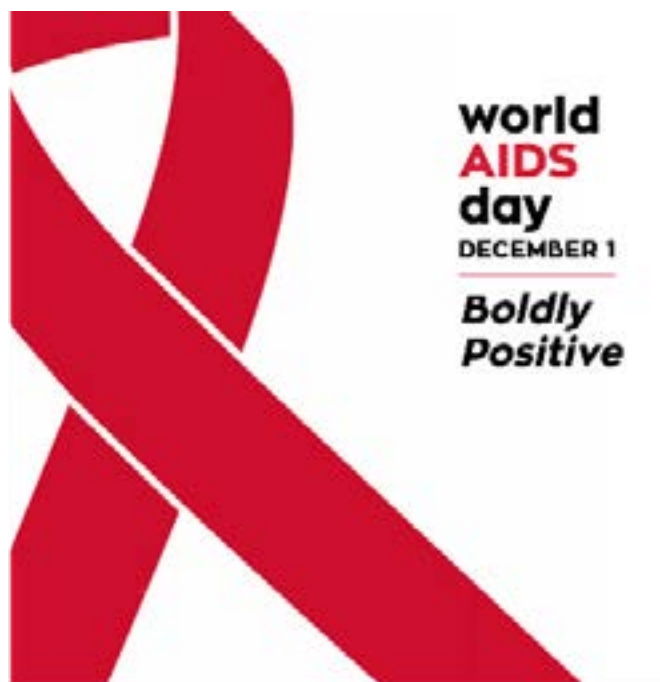
HIV IN THE BLEEDING DISORDERS COMMUNITY

This is a time when we are mindful of our community members living with HIV and commemorate those with HIV who have passed away. It is also a reminder to bring this awareness to our everyday life as a community.

HIV is an important part of our community's history. In the mid-1980s some people with bleeding disorders acquired HIV from their clotting factor treatment products. Treatment product safety is now greatly improved and the risk of bloodborne infection products manufactured from blood is extremely low. However, the impact of HIV has been profound - on the people who acquired HIV, their partner, family and friends, the health professionals who have cared for them, and the bleeding disorders community generally.

The HIV experience drew on the resilience that was already a strong element among people with bleeding disorders and led to a resolve to respond as a community, taking on effective advocacy around safer treatments and providing support.

Living with a bleeding disorder can have its challenges and peer support is valued



by many. Our bleeding disorders community is diverse but comes together with an aim of valuing everyone for their mutual support, inspiring stories, and shared lived experience. When our affected community was asked about what they would like to see in peer support, they said that acknowledging and hearing their experiences is immensely important. Creating an environment where our members with HIV can thrive also involves recognising and respecting individual preferences. Every person or family affected by HIV has their own story or way of dealing with it. Some have spoken openly about having HIV or their experiences while others are very private; some prefer not to dwell on the past; others find it very difficult to think about the future. It can be important for some to commemorate those they have lost.

Our Foundations are committed to making sure their community activities provide a supportive and inclusive environment, which takes all of this into account.

This article was written by Haemophilia Foundation Australia and printed with permission.

Read **40 years of HIV - where to next?** for reflections from our affected community about their experiences and thoughts about the future:
<https://tinyurl.com/HFA-40-years-HIV>

For more information about World AIDS Day, visit: www.worldaidsday.org.au.

International AIDS Conference 2022: HFV Report

Yarrow Ruane

From 29 July to 2 August, I was fortunate to attend the virtual 2022 International AIDS Conference (IAC). Held every second year, the IAC is a chance for community leaders, scientists, and policymakers to share research and projects related to HIV/AIDS. The 2022 IAC focused on re-engaging communities and discussing scientific research. People presented on a wide range of topics including clinical and other sciences, politics, human rights, community programs, leadership, and global development. Several discussions were particularly relevant to the bleeding disorders community.

Emerging issues for people living with HIV

The COVID-19 pandemic placed significant stress on people living with HIV (PLHIV) and threatened community support structures. Community leaders around the world are concerned that COVID-19 will exacerbate the perceived “energy drain” from HIV+ communities and advocacy over the past decade. According to researcher Bruno Spire, HIV activists in the 1980s and 1990s were often able to shape policy due to the immediacy, emotional salience, and widespread prioritisation of HIV/AIDS. As HIV increasingly becomes a chronic disease that must be managed long-term, Spire argues that policymakers require more scientific evidence, and are less invested in community contributions.

Learning from HIV and COVID-19

Many presenters discussed the unique

experience of working with PLHIV over the course of the COVID-19 pandemic. In one session, Christian Acosta, Naoual Laaziz, and Maria Georgescu discussed how their organisations supported PLHIV in Ecuador, Morocco, and Romania respectively. Each emphasised the importance of involving and coordinating community members in the face of uncertainty. Just as infrastructure and community networks formed to combat HIV were used to lessen the impacts of COVID-19, many groups anticipate that community lessons learned over COVID-19 will ultimately improve future access to health-care and social support for PLHIV.

Key takeaways

An overarching theme of the IAC was community involvement in HIV policy and research. Over the last 40 years, communities have lobbied successfully for access to HIV treatments and harm reduction guidelines. The Australian bleeding disorders community itself has been no stranger to patient- and family-led advocacy, for which we should be proud. As health policy landscapes change, however, it is important that we keep community-engaged research and practices at the forefront of our minds. Community connectedness has already allowed our small organisation to achieve great things. With an increasing array of ways to stay connected with one another, we hope to also find new ways of empowering members of the bleeding disorders community.

Additional thanks go to IAC rapporteurs Ines Alaoui, Paul Kidd, Teddy Cook.

Looking Back at 2022

By Yarrow Ruane

2022 saw HFV members easing back into attending community events. This year, we hosted seven events across Victoria. Things kicked off with our annual Community Camp, at Lake Dewar Lodge in Myrning. This was a chance to catch up with old friends and welcome three new families into the HFV community.



Over winter and spring, HFV organised two youth-focused events - an indoor rock-climbing day, and a city-based “incredible race” challenge for teenagers. After a difficult couple of years, it was great to see young people from the community having fun out and about. We are also excited for our youth to take on more leadership roles in 2023 through the upcoming HFV youth camp.





We brought in Bleeding Disorders Awareness Month (October) by painting Gippsland red with HFV's first post-lockdown regional visit. Next year, HFV is looking to visit Geelong, Ballarat, Shepparton, and Seymour.



October was rounded out with the Bleeding Disorders Awareness Walk around Albert Park Lake. We were blessed with sunshine and a cool breeze on the day. Thank you to everyone who came along, and special thanks to those who brought along their loved ones.





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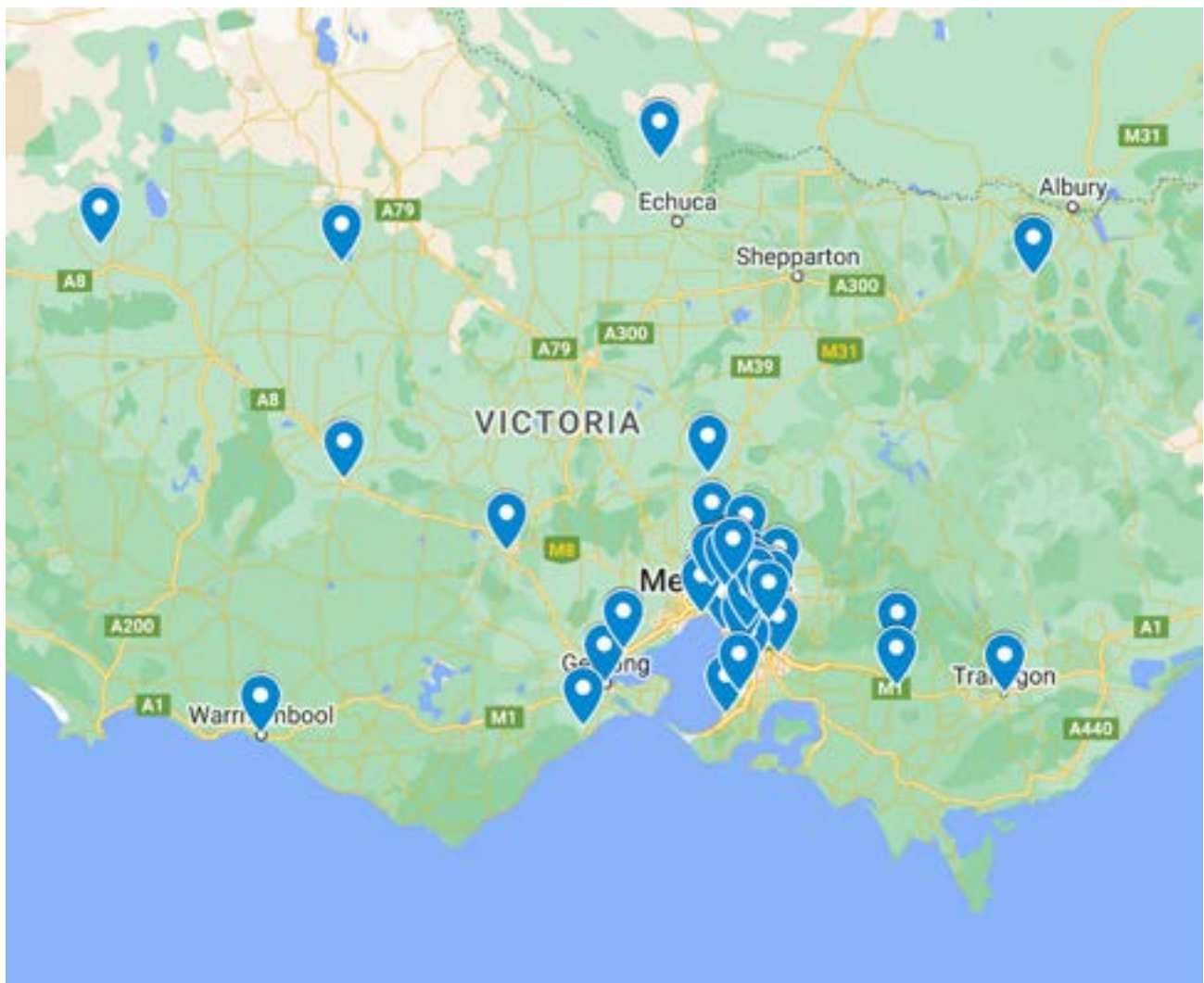
The last event of 2022 was the HFV Summer Picnic along the Yarra in Fairfield Park. Santa's elves handed out presents as we shared a small feast.



What was our 2022 event reach?

Although many of us have become disconnected over the last few years, it is nice to be reminded that the bleeding disorders community stretches far and wide. This year, people came from all over Victoria (and even interstate!) to attend HFV events. Check out our map of 2022 event attendees - are there any places that surprise you?

Areas that HFV event attendees travelled from in 2022



Notices & Information

END OF YEAR ACKNOWLEDGEMENTS

HFV are extremely grateful for all the support we receive from both within the bleeding disorders community, and the broader Victorian community. In 2022, we received funding from a variety of sources including:

- Personal donations from our generous HFV members
- Individual event donations for food and merchandise
- Workplace fundraisers
- Event fundraisers, including a garden party and interstate bike ride
- Bequests and end of life arrangements
- Commonwealth Bank Staff Foundation Community Grant
- The Victorian State Government
- Flora and Frank Leith Charitable Trust
- Ritchies Community Benefit Program

As always, HFV is also supported through the generous donation of peoples' time and energy. We would like to thank everyone who has volunteered or contributed expertise to HFV in 2022. Special thanks to our volunteer committee members:

Leonie Demos, President
Dan Korn, Vice President
Bernard Paes, Treasurer
Donna Field, Executive Member
Zev Fishman
Ben Inglis
Chris Phong

WOULD YOU LIKE TO JOIN OUR COMMITTEE?

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

We are accepting expressions of interest (EOI) now for 2022/2023 Committee of Management (COM) positions.

Requirements:

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

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

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

LIFE MEMBERSHIP NOMINATIONS OPEN

Do you know someone with a longstanding commitment to the Victorian bleeding disorders community?

Send us an email with their details and tell us why you are nominating them:
info@hfv.org.au



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

PATRON: Dr Alison Street AO

EXECUTIVE ASSISTANT

Andrea McColl andrea@hfv.org.au

COMMUNICATIONS COORDINATOR

Yarrow Ruane yarrow@hfv.org.au

COMMITTEE OF MANAGEMENT:

PRESIDENT Leonie Demos

VICE PRESIDENT Dan Korn

TREASURER Bernard Paes

EXECUTIVE MEMBER Donna Field

GENERAL COMMITTEE:

Ben Inglis

Chris Phong

Zev Fishman

VICTORIAN HAEMOPHILIA
TREATMENT CENTRES



Henry Ekert

Haemophilia Treatment Centre

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

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

Ronald Sawers

Haemophilia Treatment Centre

The Alfred, 1st Floor, William Buckland Centre
Commercial Road, Melbourne 3004
P. (03) 9076 2178 E. haemophilia@alfred.org.au

Professor Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Kara Cordiner | Haemophilia Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | Physiotherapist
Catherine Haley | Physiotherapist
Diana Harte | Psychologist
Debra Belleli | Data Manager

Membership Annual Fees:

\$33.00 Standard family membership

\$16.50 Concession / Allied (Youth Free)

\$55.00 Organisational member

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

Ambulance Subscription Subsidy:

To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee.

(Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:

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

MedicAlerts

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

Live Well Funding:

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

Care and Counselling:

This is available through your treatment centre.

Magazine:

MEN'S GROUP

Our current group meet for their Annual Men's Retreat - a much needed weekend away that included massages, relaxation and meditation. In 2022, 11 members attended the retreat, including a Tasmanian! Many promised to return after making powerful connections with their peers. There are also opportunities to meet for brunch and lunch during the year.

WOMEN'S GROUP

The group meets once a year over lunch and each alternate year get to enjoy an event with a twist. They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant. If you have an idea for a ladies day, let us know! We are always looking to try new things.

YOUTH GROUP & BLUE SHIRTS

After a successful reunion at 2022 community camp (with lots of new leaders coming on board) the Blue Shirts will be meeting up in September 2022 for an Amazing Race through the Melbourne CBD. HFV have lots of leadership opportunities available for young people looking to have fun and challenge themselves.

GRANDPARENTS GROUP

WE ARE CURRENTLY LOOKING FOR A NEW CONVENOR FOR THIS GROUP. IF YOU ARE INTERESTED PLEASE CONTACT THE HFV OFFICE.

KIDS EVENTS

We have opportunities for kids to connect throughout the year. Recently, several families met for an indoor climbing day. Check out our events schedule for upcoming kid-friendly activities.



HAPPY HOLIDAYS TO EVERYONE
OFFICE REOPENS 23 JAN 2023

