SUMMER 2023

THE MISSING FACTOR

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Travelling The World With Severe Haemophilia

HAEMOPHILIA FOUNDATION VICTORIA INC
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SUMMER 2023

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.

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

VICTORIA Australia

Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

PRESIDENT'S REPORT

Dear HFV Members,

I hope this message finds you well, surrounded by the warmth of the holiday season and the joy that comes with your family's traditions. Erika and I don't have any extended family here in Victoria so we're working on building our own traditions as a family; just this morning we strung the lights on our tree and hung ornaments all over it. As we come to the end of 2023, I am filled with gratitude for a safe and healthy year, but I'm also a little concerned.

I don't actually know how long it's been since our last round of COVID lockdowns, two years and change sounds about right, but despite the passage of time I can still sense the mark they left on our bleeding disorder community. It's now much more common for HFV to withdraw events at the last minute due to low interest.

Our wonderful staff Andrea and Yarrow put in extra effort each month to email, ring around, and post on social media to remind members of upcoming events, and while that does help tremendously, many of our smaller catch-ups are seeming to wilt away.

This includes gatherings like our regional and rural visits, where HFV committee members and the staff set up meetings throughout Victoria to make sure all of our members have a chance to be heard. I'm especially concerned to see these be postponed or cancelled because changes in hospital routines make it much less likely for us to meet each other casually in a waiting area at the clinics. If we don't make a point of meeting under the auspices of HFV, it's possible we'll lose the sense of community that makes our peer support work so well.

It's critically important to me that people from all across the bleeding disorder community feel connected to each other and to HFV. I'm always happy to pick up the phone or text with someone who's having trouble with their condition or their treatments and support them as best I can, and I know many of our members turn to each other for informal help too.

But the idea to pick up the phone and ring around for advice when you can't reach your GP after hours depends on us establishing trust and friendships in the first place. In my experience those bonds often grow from seeing each other at a Young Families' Day at a park, or when we catch up at a café in a town nearer to you than to the HTC.

So please do let us know if you have an idea for an event we could put on once or twice a year that you'd like to come to. And in the same vein, if you have suggestions for how we should change some of the events we plan for the year, we would love to know what you think could be better about them.

With all of that in mind, I'm excited to report on our Bleeding Disorders Awareness Month walk at Albert Park Lake. Despite the blustery breezes, it was a resounding success with over 70 attendees enjoying the sunshine and each other's company.

We are also already taking registrations for our Community Camp in March 2024. I look forward to seeing you at Mill Valley Ranch in Tynong North.

PRESIDENT'S REPORT

There will be a barn dance for all ages, a wide variety of youth activities, the Secret Men's Business and Secret Women's Business discussion groups, horse riding for teenagers and adults, and horse petting for children.

If you're planning to come along it would be a huge help to us to get an RSVP soon, so put this magazine down, check HFV's website for the booking link under the "Get Involved" heading, and register today.

Finally, as always, we are keen to make sure a broad variety of people from our community are members of the management committee which sets HFV's plans. In particular it would be good to have more people join who have VWD or are fathers of young people with a bleeding disorder. If you would like to sit in as a guest for a committee meeting to see how it goes, that can be as simple as clicking on a Zoom link. So please reach out to Andrea for more information.

On behalf of all the volunteers and staff at HFV, I wish you and your loved ones a joyous holiday season in full health and overflowing with warmth and laughter. Let's be sure to catch up in person in 2024, and if there's anything I or the HFV staff can help you with, just ring us. We'd love to hear from you.

With heartfelt appreciation,

Dan Korn **HFV President**

HFV COMMUNITY WEEKEND

15-17 MARCH, 2024

ABOUT

Join us for a weekend away with others who know what it's like to live with a bleeding disorder!

The HFV Community Weekend is always a highlight of the year, with families and community members coming together to relax, laugh and (sometimes) push their limits! The 2024 program includes horse riding, barn dancing, private men's and women's "secret business" meetings, and activities for children of all ages.

LOCATION

Mill Valley Ranch
525 Tynong Nth Rd
Tynong Nth

https://www.trybooking.com/CLPVR

Donna's insights: The benefits of spending time with horses

Hi, my name is Donna Field, and I am a HFV Committee member.

I have been involved with horses since I was 10 years old. From the time I could walk and talk, all I ever wanted to be around were horses. At the age of 10, my mum eventually gave up saying "No" and bought me my first horse. I trained that horse from an inexperienced two-year-old Arabian gelding through to a highly educated and successful competition horse.

I am a qualified horse-riding instructor and I judge and regularly teach at four Pony Clubs throughout the year. I have been teaching at Pony Club for over forty years now.

I am excited the HFV Community Weekend next year will be at Mill Valley Ranch. Many of you who have never been involved with horses will get to see and do what I love.

Horses are highly intelligent animals and can read your emotions on a level completely different to other animals. Horses are unique in that they don't judge. They give unconditional acceptance, reacting to your behaviour and emotions. They are great at observing and will often mirror your behaviour.

When adults and children interact with horses, research has shown they may experience benefits like reduced stress levels, reduced tension, lower blood pressure

and increased confidence. They can improve a person's feeling of self-worth and enable you to obtain a calming presence.

If you allow yourself to, you will have a very special experience at the Community Weekend in 2024. The experience will tap into your heart, soul, trust level and for some, help you overcome your fear.

I look forward to seeing you all there.

Donna Field
HFV Vice President

Member Q&A with Lenny:
What's it like to work in tech research?

My name is Leonard Mammoliti, 31 years old and a HFV member since I was just a few weeks old. My interests include Lego Technic (the more complex and challenging the better even though it takes me a while to put it together or start all over again when I lose a tiny but essential piece), playing/analysing my piano pieces, and attending MSO (Melbourne Symphony Orchestra) concerts especially the 'Ears Wide Open' series or when a well-know pianist is playing in town. In addition, I thoroughly enjoy well-crafted comedy shows or sketches and like many, playing computer games.

There is a family history of moderate haemophilia A from my mother's family. Unfortunately I had a cerebral haemorrhage at birth and was rushed to RCH at 7 days old. The percentage of factor was diagnosed properly about 2 weeks later.

Can you tell us a bit about your current job?

I currently work for La Trobe's Centre for Technology Infusion (CTI) as a casual researcher. My job description is 'Supporting the Deputy Director in desk research, analysis, reporting, and coordination of projects.' Specifically, I have been involved in testing and reporting on the accessibility of new technologies to assist people with disabilities in public transport, healthcare, and mobility.

What led you to this field?

Before this job opportunity was offered, I volunteered as a usability tester for Vision Australia on a couple of occasions and found that I thoroughly enjoyed it as I have benefitted from the computer right throughout my eduction since Kindergarten. The digital devices helped in my daily organisations and mobility as well.

When a 3-month internship was offered I enthusiastically applied for it because it combines my lived experience of disability with my passion and curiosity for new technology and how it can enhance the lives of people with disability. Fortunately, I was delighted when the 3-month internship was extended to 6 months and I was then offered a permanent casual position.

What achievements are you particularly proud of?

During my first month into the internship, I was tasked in attending and reporting on a series of six focus group interviews. With the guidance of a PhD student, the project was a great success. I was proud when my name was included on the front page of the report.

I was asked to compose a short description about my role to be incorporated into the 'Researchers' section of a recent report. It makes me feel included in the team, and my contributions are valued.

What goals are you working towards?

I am excited that there is a big future in deploying technology to assist the disabled community in gaining improved living standards, education, and employment. I would like to learn further how we can make these technologies more affordable to make life more inclusive for people with disability in our society, as well as

other communities in the world.

What does it take to succeed in your role?

I think the combined training I had in university in research, analytical work as well as noticing all the fine details in the music major, and different reporting and writing styles in the psychology major and combined with lived experienced have contributed to my success. In short, having an analytical mindset yet being open-minded to other people's needs. There are so many types of disabilities and everyone has different requirements to improve their conditions.

Do you have any core values that you live by?

Having Haemophilia alone is challenging enough for anyone. At times, it has been overwhelming living with additional complex disabilities namely a rare vision impairment and mild cerebral palsy. I think it takes a lot of courage, resilience, tenacity, and acceptance of one's conditions, especially when realising that you are quite different from everyone else. Thinking creatively to find different solutions and being comfortable with uncertainty, failure, and concentrating on a growth mindset often helps. Most importantly, being grateful for all the positive opportunities in my life and the people, especially my parents, who have helped me along the way.

What advice would you give to your younger self?

I would tell myself that having a disability doesn't define me as less worthy than others. Even though many times I have faced insurmountable challenges or criticisms from others, I must never give up because there are talents in me that I have not discovered yet. You never know what opportunities are out there when you open your mind.

Final thoughts...

I am most fortunate to be working in a supportive environment with a team who believes in improving the lives of people with disabilities using technology. I am grateful to be given the chance to continue learning and demonstrating my skills. I am glad that my efforts and contributions are appreciated. It's so exciting to discover new technologies that are being developed and trialled in Australia, as well as overseas. Even though the lives of many people with disabilities will not be transformed overnight, but hopefully their future will be better and brighter one day soon. It's also eye-opening to see that end-users with disabilities are active participants in the development, testing, and evaluation of applications/mobility equipment aimed at improving their lives.

A PATIENT'S EXPERIENCE WITH GENE THERAPY

By Dan Korn

Now that Australian regulators have approved gene therapy treatments for severe haemophilia, there's a lot of interest in what it's like. In particular, now that so many of us have access to Hemlibra, people are puzzling over a question no one in the bleeding disorder community would have foreseen a decade ago: "Now that gene therapy is here, is it actually better than my standard treatment?"
I can't answer that question directly. It's strictly a matter for you, your family, and your HTC. But I can tell you what gene therapy is actually like, because I had it done six years ago.

I was born with severe haemophilia B and grew up in the USA. Since the late 90s I've been keeping an eye on the progress of gene therapy; at one point around the turn of the millennium I was approached about participating in a very early-stage gene therapy study. I decided not to join in then, more because I was struggling a bit at uni than because of anything specific about the therapy or the researchers.

But despite turning down that early study I kept up with the researchers' progress over the years. After moving to Australia in 2014 I started hearing about a new round of gene therapy being developed which built on the lessons learned in earlier studies. I'll spare you the full list of the many rounds of "should I volunteer or not" discussions with my wife, my parents, my HTC in Melbourne, and the research team in Sydney. Suffice to say it took several years from the time I first spoke with the study team until the day the medication was actually administered. So if you're on the fence about gene therapy, don't feel like there's any big rush for you to make a decision either.

While undergoing gene therapy was a momentous occasion in terms of my life with haemophilia, the actual administration of the product itself was almost a non-event. I sat down for an hour to let the IV drip through the lines, I stuck around for the rest of the day so they could take blood samples at specific time intervals, and I felt absolutely no different as it happened nor afterwards. The treatment itself took several weeks to come into full effect, so I think I even took a dose of my normal factor IX medication when I tripped getting off a bus and badly twisted my ankle.

After that initial wait for the gene therapy to kick in, I didn't need any more factor for the rest of the year. I personally would have been ecstatic to go from less than 1% factor IX activity to 14%, since that's the point at which people with haemophilia have almost no spontaneous bleeding. But my levels quickly stabilized in the high 30s. For context, that's as much as I'd have in the hours after taking a dose of my usual factor product. This was a fantastic result, because gene therapy means I was maintaining this level 24/7, rather than peaking after an infusion and then falling back to single-digit percentages within two days.

So what was the overall effect for me? My family and the HTC I grew up with in South Carolina always pushed me to be as independent as possible, and I probably took that encouragement and went too far with it. Even while taking 50-70 doses of factor a year, I managed to

Trillions of AAV gene vectors fit neatly into one single IV bag.

travel away from home and even go overseas with my family. When I finally finished uni I moved to Singapore and Cambodia to work there for several years. So, even before gene therapy, while there are some everyday activities that I avoided due to my haemophilia, I did everything I could to not let it limit my life goals.

Even knowing that I could be so independent with regular Factor IX treatments, though, I feel liberated by having a successful gene therapy treatment. There's almost no chance anymore that I'll need to take time off work to manage a bleed. I don't have to deal with fitting my exercise schedule to my prophylaxis schedule. I even feel confident traveling overseas but not taking any factor with me. From the point of view of managing bleeds and joint damage, it's hard to understate the positive impact gene therapy has had on my life.

That's not to say there weren't any drawbacks. There was a dramatic and unexplained drop in my factor levels from the high 30s to the mid 20s. Strangely this happened around the one-year mark after my gene therapy, rather than steadily falling over time. Even now that it's stabilized there for five years, I worry that it might drop again for some reason. So while I'm grateful for a fantastic outcome to what was at the time an experimental treatment, I'm mentally prepared for the possibility that it will wear off some day.

Another thing to consider was that about two months after the gene therapy dose, I did have to take a course of corticosteroids when it appeared that I was having an autoimmune reaction. While it was a bit of a downer to be more irritable and bloated than usual, it was no big deal to me in the long run. It only lasted a few weeks, my factor IX activity didn't drop off at all at that time, and I'd gladly go through it again in order to support a successful outcome.

A week or two of standard side effects is an easy trade for me to make in the big picture because a successful gene therapy means never having to keep track of a prophylaxis schedule again. It means almost entirely cutting out bleeds and further deterioration in my target joint. While I've had a few bleeds there, they develop much more slowly so it's much easier to stop them early. And of course two or three bleeds over six years is many fewer than I had when I was using my regular factor-replacement product.
In fact the major drawback to my gene therapy has been more of a social challenge than a medical one. It was recommended that I limit my alcohol intake to just one standard drink per 48-hour period. While that wasn't too big of a change from

The big day. Medications and cannulas at the ready, posing for posterity with Dr. John Rasko and his team.

my usual pattern, it's a bit confronting to realize most drink servings at your local are more than one standard serve of alcohol per glass. So I've had to cut out anything but the mildest drinks. Holding yourself to just one round every few days can be really difficult in a country where it's so common to share rounds of drinks after work or have several glasses of wine to celebrate a big event.

Younger generations are more accepting of people choosing not to drink alcohol, but that's a far cry from everyone being accepting. I've had several really poor experiences where people I've just met at after-work drinks are badgering me to have another drink or three to keep up with the group, and they just won't take no for an answer. They may think of it as harmless, jovial encouragement, but I don't wear my haemophilia on my sleeve, so to speak. I've got no obligation to share that part of my life with near-strangers, and it would be a real drag to try and explain the ins and outs of gene therapy to them.

So the overall effect is that I tend to avoid those gatherings now in order to make it easier for me to stay compliant with the recommended alcohol limits. That's not a great outcome, but it's a trade I'm willing to make at this point in my life. If I were younger or if I had close friendships that centered on nights out on the town, it's something I might really regret.

Summing up, what advice would I offer someone weighing up continuing their current clotting factor routine vs going the gene therapy route? I don't think I can really make that decision easy for you. It's something you have to weigh up carefully, and be really honest with yourself about each factor in the decision. Only you, your family, and your haematologist can understand all the pros and cons of each treatment and how they mesh with your life. Think about what you want to do with yourself over the next decade or two and identify which kind of treatment routine would best support help those goals.

For example, if you're thinking of moving overseas for a long time, gene therapy could be a huge help. The same goes if you're having trouble keeping track of your current treatment schedule or keeping the supplies at your home. On the other hand, if you have a routine that works really well for you now, and you don't have many breakthrough bleeds or a target joint, the drawbacks might not outweigh the benefits. My advice is just to be really honest with yourself when you're assessing the balance. A clear understanding of how well you're doing now will help you make the best choice for your future.

My Amazing Travel Adventure: Jack's Story

Jack talked to HFA about travelling overseas and managing his haemophilia for some amazing trips!

Where did you go on your trips?

I've done two separate trips over the last couple of years.

With my first trip, I went to Southeast Asia for about five weeks, mainly around the south of Vietnam and Thailand. I went with one of my best mates who I've known for years. We travelled at a pretty fast pace, moving to a different city every couple of days, about 14 different places across the five weeks.

With the most recent trip, I went to Europe for about 7 weeks with my girlfriend. I flew into England and started in London. My girlfriend's family is from Wales, so I went across to Wales for a week or so.

Then we did a group tour, where we made some great friends and continued to travel with them following the tour. It was pretty similar to the earlier trip - we moved around really quickly and I went to about 12 countries. I started in England then went down through France, Switzerland, Spain, Monaco, Italy, Austria, Czech Republic, Germany, the Netherlands, Belgium and then back to London again, and then came home to Australia after that.

It was really exciting.

What were the highlights for you?

Some highlights of my trip to Asia were Dalat in Vietnam, a small town up in the mountains, which was really cool. I also loved Hoi An, with its old lanterns and unreal food - just an awesome vibe there.

Then in Thailand we did an island-hopping cruise around

"With my first trip, I went to the south of Vietnam and Thailand with one of my best mates who I've known for years."

the Phi Phi Islands - amazing crystal-clear waters and reefs. I also loved another small island called Koh Tao, which is a tiny little speck on a map. It's where a lot of people get their diving licence. It was just unreal beaches and scenery.

When we went to London, I got to go to an EPL (Premier League) game to watch the soccer, which was pretty sick. I also went to Printworks. I'm a DJ and I love my electronic music. Printworks is one of the biggest venues in the world, so going there was awesome. It's actually closing down soon so it's cool we caught that before it finished up.

And going skiing in Austria was just unbelievable. It was the middle of winter, so it was freezing. But we had some 'bluebird days' where it was perfect weather whilst we were on the slopes! It was my first time skiing. We just skied because in Austria there wasn't a heap of snowboarding. But when I go to Canada later this year, I'm going to give snowboarding a crack and we'll see how that goes.

How did you prepare to travel with your haemophilia treatment?

When I'm preparing to travel to another country, my first thing is to quickly check requirements in each country and make sure I am not bringing anything in that is illegal. It's important to know, especially when we're going to Asia or countries where they speak a different language. I get letters from the hospital to carry with me, so if I do ever get pulled up in customs, I have letters to explain why I'm carrying needles and treatment.

I usually have a meeting with my haemophilia nurse about eight weeks before I go away. We discuss a plan on how to tackle how much treatment I will need to bring to ensure they order enough treatment, as well as organise the doctors' letters.

Then I make a plan of how to keep treatment cold, which is one of my biggest challenges. Not all hotels have fridges, so I come up with the worst-case scenarios, like a plan for keeping my treatment cold if I have a 12-hour travel day, or have a hotel

"I loved the small island called Koh Tao - just unreal beaches and scenery"

that doesn't have a fridge.

Then finally, I always make a list of where the Haemophilia Treatment Centres (HTCs) are, just in case of any emergency. That was a bit harder in Asia, because there weren't as many HTCs. But in Europe there were plenty, so if anything did happen, I had an HTC where I could go and see some knowledgeable doctors.

How did you manage your haemophilia while you were travelling?

I had two different experiences of managing my haemophilia when I was traveling.

During my first trip I was using factor VIII (8) products, which required far more frequent treatments. After discussions with my haemophilia nurse and doctor, I was having one treatment per day when I went to Asia. This meant I had 35 doses, which was a challenge to carry that amount of factor VIII over there. But the biggest challenge is temperature, especially in a hot climate like Asia, and keeping that much treatment product cold for that long.

Printworks in London is one of the biggest venues in the world, so going there was awesome

It was a stark comparison to my second trip where I was using a non-factor product. I only needed to bring 3 treatments with me, which was much easier to keep cold, plus it was winter, so it was a completely different scenario.

I also needed to make sure I had correct travel insurance that included haemophilia, so that in case of any emergency, I would be covered overseas.

What was easier than you expected?

I've always had some form of anxiety that I would be pulled over and questioned why I have all these needles and syringes in my carry-on luggage, but I've never been stopped at customs either in Asia or in Europe. Which is nice!

Did you need to do anything special in the group tour?

There were a few extra considerations with the group tour. The main thing was discussing my condition with the tour manager so he was across it, in case of any emergency. There were also quite long bus rides. I discussed it with my tour manager and he allowed me to use the fridge on the bus to keep my treatment cold as well. But

"The biggest challenge is temperature, especially in a hot climate like Asia, and keeping that much treatment product cold for that long."

aside from that, I found as long as I was transparent and up front with the tour manager so he was aware of the health condition I had, it was no drama, really.

Apart from the tour managers, haemophilia is something I've normally kept to myself on my trips because I think as long as you manage it correctly, it shouldn't affect the way you live. Obviously, my girlfriend was across it and when I travelled with my friend, he was across it, so they're aware in case anything happened on the trip. But aside from that, I never really told other people.

Will you do anything different on your next trip?

My next trip will involve skiing in Canada, so there's probably going to be a bit more risk if I fell off a snowboard or something like that. Now that I am on non-factor therapy, that might mean carrying some extra factor VIII with me, just in case I did have a fall so that I have a bit of factor VIII to manage a bleed. But I'll discuss that with my haemophilia team when I am closer to the trip.

What travel tips do you have for other young people with bleeding disorders?

My main travel tip is to plan for every scenario and discuss this with your haemophilia nurses and doctors.

I suppose the biggest concern with going away is you are a long way from home. If your parents are anything like mine, they will be extremely worried!

So have a plan to make sure

"When I go to Canada later this year, I'm going to give snowboarding a crack and we'll see how that goes."

"My main travel tip is to plan for every scenario - so you can go on your trip with confidence and travel freely."

you're never going to be stuck, you're always safe, you always have treatment with you and just be across everything you need to be so you can go on your trip with confidence and travel freely.

Want to know more about travel?

Visit the Travel section on the HFA website: https://tinyurl.com/HFA-travel

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

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World AIDS day 2023

Friday 1 December

World AIDS Day is marked globally on 1 December to raise awareness about HIV and eliminate stigma and discrimination. In 2023 the national theme for World AIDS Day is Inclusion, Respect. Equity.

Part of our everyday life as a community is being mindful of our community members living with HIV, of demonstrating our support for them and honouring lives lost over the past 40 years. Wearing a red ribbon on World AIDS Day is one way of showing your support.

Much has changed since HIV was first identified in the mid-1980s. Today in Australia people living with HIV can get medication that allows them to live a healthy, long life, suppressing their viral load so they have no risk of transmitting the infection to a sexual partner. There are also medications to prevent HIV infection if exposed to the virus.

HIV in the bleeding disordders community

HIV is a very important part of our community's history. In the mid-1980s some adults and children with bleeding disorders acquired HIV from their clotting factor treatment products. Some lost their lives to HIV while others live with HIV today. Treatment product safety is now greatly improved and the risk of bloodborne infection from products derived from blood is extremely low. Nevertheless, the impact of HIV has been profound, not only the people who acquired HIV but those close to them, those who have cared for them and the 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.

Inclusion.
Respect.
Equity.

This year's theme is a timely invitation to consider what Inclusion. Respect. Equity. means to us.

We are grateful to some of our community members living with HIV who generously shared their thoughts.

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

Neil

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

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

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

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

Mike

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

But what do these words mean to our bleeding disorders community in Australia? Those of us who have lived with HIV for over 40 years, and those of us who have seen loved ones succumb? I often feel like our part in the story of HIV/AIDS gets forgotten. While the increasing dissociation of HIV/AIDS and bleeding disorders creates safety for us, it denies our truths and remarkable achievements too. Whether you mark World AIDS Day privately or publicly, or not at all, please know that you remain part of a community that is extraordinary for its resilience and dignity in the face of bloodborne viruses."

Anth

*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*

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

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

GOING TO MY FIRST BLEEDING DISORDERS CONFERENCE

By Debbie Tenace

This year I had the privilege of attending my first Australian bleeding disorders conference. I really had no expectations before attending, other than being a great opportunity to reconnect with our wonderful supportive community and to keep abreast of what's happening in the treatment space.

The morning started with an overview of the treatment landscape into the future. I found it enlightening to hear from Jo Cameron, who explained the process of obtaining access to new therapies, policy, regulation, and funding. I really had no appreciation for how extensive the process to obtain funding is and it was comforting to hear someone who works within that system being so supportive of our community's cause. We often yearn for new products or scientific developments to help our lives without adequate consideration for how we can actually practically get access to these treatments. This is such an important part of the process and I have a much better appreciation of this process now.

After a lovely morning tea and catch up with friends, I attended the gene therapy session. What I took away from this session was that gene therapy is not without its risks. It really is a long-term commitment and with the availability of a product like Hemlibra, gene therapy may not be the right option for all (or even many) of our boys right now. The pros and cons really need to be weighed up. I had no idea that long term steroid use may be required, liver complications and the need to freeze sperm. It really is early stages and I think the analogy was we are at the equivalent of iPhone 5 and really need to get to iPhone 10 or 11 before this becomes more mainstream.

After another break for lunch, I attended the session on the impact of new treatments. It was very interesting to hear the feedback from families and professionals

"We are at the equivalent of iPhone 5 and really need to get to iPhone 10 or 11 before this becomes more mainstream."

on how everyone is managing on the new treatment. Interestingly many of the boys are finding the new treatment process a little confronting. This resonated with me, and I came away with some very helpful tips for my son.

It was wonderful hearing the community reflections. In particular Claire, Catherine and Lachlan. They all did an amazing job giving us an insight into their families' journeys. It was interesting to see how the professional staff attending were extremely engaged in the session with Lachlan and asked many questions about Lachlan's experience growing up with Haemophilia.

And what a way to top off the day… The dinner dance! A great opportunity to reconnect with friends over great food and have a laugh and a boogie! I went home with a full belly, a warm heart, and a feeling of connectedness.

For anyone who has not attended one of these conferences before…. I encourage you to take the leap and attend... Even just for a day! We are so fortunate to belong to such a supportive community and to have such wonderful professionals fighting for our cause. I hope to see you all at the next event in Brisbane.

Debbie Tenace

A FACE-TO-FACE CONFERENCE

By Jane Portnoy

The Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders was held in Melbourne in August this year.

It was the first in-person, face-to-face conference since COVID and there was a real sense of joy from the attendees. Old colleagues and friends, patients and their multi-disciplinary teams, international speakers, and experts in various fields all gathered to learn, share and support one another.

The highlight from my perspective were the gene therapy discussions. As this is an exciting and potentially life-changing new therapy, many were very interested to hear from Dr Glenn Pierce. Glenn is the VP Medical at the World Federation of Haemophilia based in the USA. He spoke from a scientific and personal experience about this therapy, explaining how it works in layman's terms, how it can change a life, and its future potential for people with bleeding disorders.

Providing psychosocial support was also something I was delighted to be able to talk about. Like everything, if you support people there is a better chance of them being able to do all that they need to for the therapy to succeed or make the right decision for themselves in the first place. This is a huge topic, and the message was 'find out about gene therapy, talk to your team, keep in the loop about any develop-

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ments; it is a work in progress, and already working for some.'

I was delighted to attend the session on career choices across a lifetime. I found the lively discussion evidence that there is much to learn from each other, as well as from the professionals working in this field. We were lucky to have Mark Waters, who is a lawyer from CIE Legal, speaking about discrimination and disclosure, and Jon Hazelton from Bravo Careers talking about how to make decisions about what career to choose, what is important for the individual, and how to achieve success. Choosing the right path can lead to satisfaction, and more success. With consideration of your own personal limitations, such as implications of haemophilia and physical restrictions, there can be less setbacks for the individual along the way.

For me the "Getting Older" session had an animated audience discussion inspired by the formal presentations. Many of the participants had experienced a wide range of challenges and had many helpful suggestions. In the sharing of how people tackle their own personal journey, others realize they are not alone in their struggles. This helps bring about benefits like learn new ways to manage and regaining hope and support, which does make difficulties easier to live with.

I always enjoy catching up with old friends, making new friends, and sharing stories during the breaks. What a pleasure it was this year. Thanks to those who worked so hard to make the event run smoothly, the conference committee for planning such an interesting conference, the speakers, and all those able to attend for their contributions.

Jane Portnoy is a Social Worker at the Ronald Sawers Haemophilia Centre at Alfred Health. This article was written for "The Missing Factor," 2023.

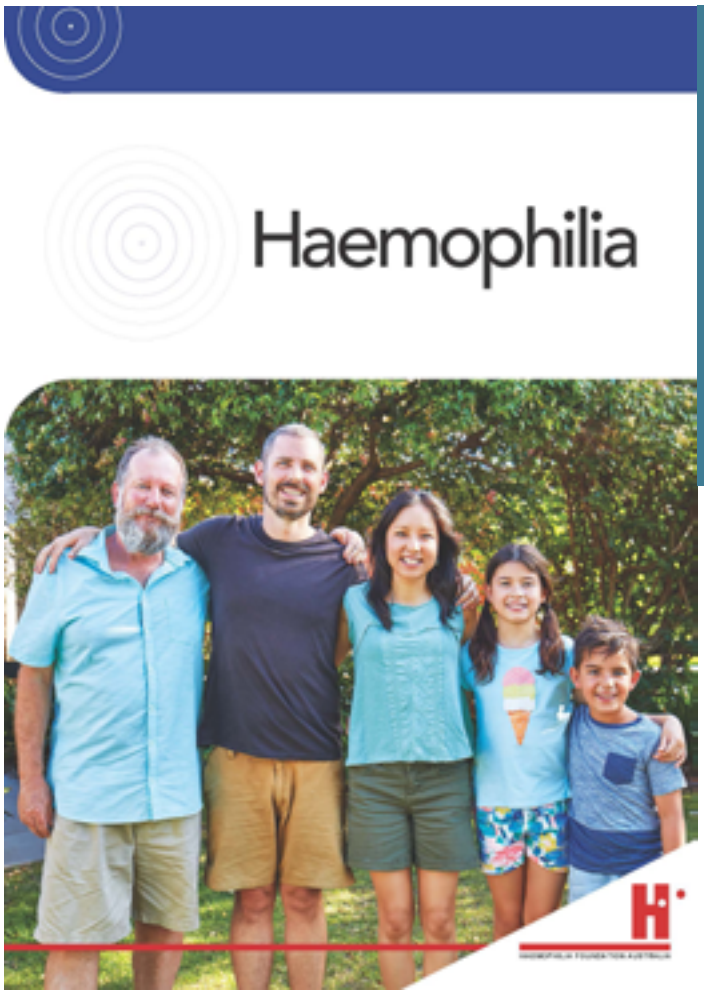
New Haemophilia Info Booklet From HFA

The new HFA Haemophilia booklet is now available. Much has changed with new haemophilia treatments and the 2023 edition has been revised completely.

It is a great introductory resource about haemophilia that is very useful for new families and educating others – for example, extended family, schools, employers and health professionals who are new to haemophilia. It covers:

- what causes haemophilia
- diagrams of genetic inheritance and how bleeding occurs in haemophilia
- diagnosis
- treatment (including new treatments)
- carrying the gene alteration
- family planning and pregnancy
- tips on living well.

Thank you to all of the community members and health professional experts who contributed to its development.



Accessing Haemophilia 2023

- download it from the HFA website

  tinyurl.com/HFA-haemophilia
- ask HFA to post you a free print copy

  hfaust@haemophilia.org.au

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Notices & Information

A FAREWELL FROM YARROW!

After two wonderful years at HFV, I (Yarrow) will be finishing up in mid-January 2024.

I want to thank you all for letting me into your lives. I am so grateful for the time we have spent together since I started as Communications Officer at the end of 2021. It has been really special getting to know you and I have learned a lot.

I have decided to study medicine next year and will be moving up to Canberra with my partner. I hope that if I bump into you in the future, it will be on the street and not in the hospital!

The committee are busy interviewing for my replacement as we speak, and I know you will welcome them just as you welcomed me.

Best wishes to you and your loved ones over the holiday season, and beyond.

WOULD YOU LIKE TO JOIN OUR COMMITTEE?

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

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

Requirements:

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

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

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

WRAPPING UP 2023

Big thankyou to all of our members for your support in 2023. Special thanks to those who have made it along to events - you make it worth the while!

The office will be closed from Wednesday 20 December and will reopen on Monday 15 January 2024.

HAEMOPHILIA FOUNDATION VICTORIA INC

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. (03) haemophilia@alfred.org.au

Professor Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Kara Cordiner | Haemophilia Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | Physiotherapist
Catherine Haley | Physiotherapist
Diana Harte | Psychologist
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:
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:
Your quarterly magazine offers information and details of upcoming events.

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. In 2024, we plan to meet for a paint-and-sip day!

YOUTH GROUP & BLUE SHIRTS
After a successful reunion at 2023 youth camp, we are excited to provide more leadership opportunities for young people in the community. If you are a young person wanting to get involved at HFV, send us an email with your age and interests: info@hfv.org.au

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 including picnics and play days. Check out our events schedule for upcoming kid-friendly activities.

NEWLY DIAGNOSED FAMILIES
We run morning teas for young families quarterly. Register your interest at: info@hfv.org.au

See you in January!

HFV office closed from 21/12 - 14/01