SPRING 2022

THE MISSING FACTOR

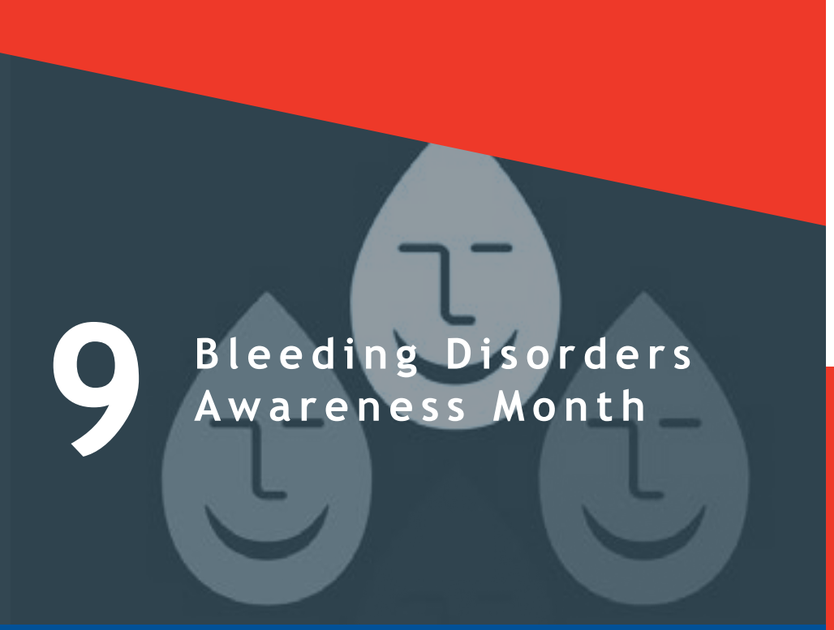
Haemophilia in Film and TV • Ask Us

Bleeding Disorders Awareness Month

Reconnecting post COVID • Notices

4 From Athlete to Business Owner: Farooq's Story

8 No More Heroes: Haemophilia in Film and TV



9 Bleeding Disorders Awareness Month

Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

SPRING 2022

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

PRESIDENT'S REPORT

Hi HFV family,

As I have had the privilege of sitting in the President chair for several years and written a few of these articles I feel I may seem repetitive. So to shake it up I just wanted to keep it brief and simple.

The magazine is jammed packed with such amazing content I encourage you to not only enjoy a good read but make sure you share it around your family and friends. The more we educate those we love the better outcomes for all our community. We are a blessed community with richness in diversity and the articles really reflect this. From the support of those like Julia Ekert at RCH and the ongoing contributions from our team at the Alfred to the insights of how Tony Sawers found the HTC 'by accident'. Scott McDonell is one of our outstanding blue shirts providing leadership in the community and his article about the media is well worth a read. And there is so much more to enjoy!

We have many upcoming events that we would love to see you at. Our walk at Albert Park Lake, the return of our regional visits, the planned Christmas events around the corner as well as our important AGM. If you have any interest in joining the committee now is the time to get involved. Everybody has so much to value add to the conversation at HFV so we welcome a chat from you to see if it may be a good fit for you. Our community is small but mighty and we need you to be a part of our work. With many in need across our state we would love to include you in the conversation.

COVID has touched close to home for most of us with either experiencing it first hand or supporting loved ones. As we come out of the bitter cold of winter and welcome our daffodils and slight hint of blossom please consider how you can support our work. Look forward to catching up somewhere soon.

Be safe!

Leonie Demos **HFV President**

From Athlete to Business Owner

Farooq's Story

Five months ago, Farooq moved to Melbourne to start a restaurant. But on his way to becoming a business owner, Farooq has lived a life full of twists and turns...

Farooq and his twin brother were diagnosed with haemophilia A as infants. Having no history of haemophilia, their family struggled to access information and healthcare for the boys. Growing up with haemophilia in Pakistan "was very hard," says Farooq. "The only treatments available were hot water bottles and blood transfusions. One time when my brother had a bleed, our mother donated the blood for him."

The two boys were resilient. "We didn't care about the haemophilia – we just wanted to play." Following in the footsteps of athletic older brothers, the twins developed a love of sport. As adults, both of them would go on to represent Pakistan at an international level – Farooq for cricket and badminton, and his brother for table tennis. Farooq was the first person with haemophilia to play with the Pakistan Disabled Cricket Association.

In the 1990s, Farooq and several friends started the Pakistan Hemophilia Patients Welfare Society (PHPWS) in Lahore. The group aimed to improve the lives of people living with inherited bleeding disorders. With the help of the World Federation of Hemophilia, access to factor treatments and support improved over the next 20 years. Treatment centres were established in Pakistan and groups like PHPWS worked to provide information to patients.

"I'm a sportsman. That's my dream."

Challenges remain for those needing to access comprehensive haemophilia treatment in Pakistan. "They are not a rich people," Farooq says. "It's not easy to get treatment and I have a pain in my heart for them." He hopes to do more in the future to support other people with haemophilia.

Farooq is proud of what he has achieved so far. "I have a family. I have a restaurant. I'm a hard worker. My kids and wife are amazing and so supportive." With all the positive things in his life, Farooq still does have one major complaint: "When will Australia get a [physical] disability cricket team?"

"Don't think of yourself as a haemophilia patient. Just think of yourself as normal!

When I have a bleed, I become a haemophilia patient. But I don't think of myself that way. "

NO MORE HEROES: HAEMOPHILIA IN FILM AND TV

By Scott McDonnell

Growing up with haemophilia, my early childhood wasn't what most people would consider normal. At birth, I experienced an internal brain haemorrhage that caused doctors to race against a ticking clock to diagnose me and figure out how to save my life. After many different trials and errors, a nurse suggested checking me for haemophilia – a blood disorder that prevents clotting in those affected.

Long stints in hospital were the norm for the first five years of my life, where the chrome and porcelain white detailing of The Sydney Children's Hospital became synonymous with the comfort that people usually associate with home. The diagnosis recontextualised what parenthood would be for my parents, as they had to learn a plethora of new terminology, skills and

> **"the path to normalcy was paved by imagination, make believe and fantasy"**

treatment to raise a child with a disorder that affects one in 5000 males. My parents worked hard to make me feel normal, so that I never felt defined by my disorder and never felt like an "other." My parents, and the nurses and doctors around me, helped me develop through film and tv, toys and books. What could be a traumatic experience for a young child, they made fun and exciting. For me, the path to normalcy was paved by imagination, make believe and fantasy. Particularly, I loved superheroes.

The transfusions of synthetic factor VIII I received three times a week were followed by me running around in a superhero costume of my choosing. Instead of being scared by transfusions, they became how I got my "powers." Mild-mannered four-year-old Scott McDonnell would receive a fantastic injection that granted him the powers of Superman, Spiderman or... Bob the Builder for some reason. When I had factor, instead of feeling different or fragile, I was strong, confident and unstoppable in what I wanted to do. In the hallways of a hospital, so distant from reality that it may as well have been the distant planet of Krypton, haemophilia was my superpower – and there was nothing I couldn't do.

When it came time to pick sports as a kid, I dipped my toe in anything I could find – usually only for a couple of months. I rotated through Auskick, Soccer and very briefly Baseball, but the activity that really grabbed hold of me was Karate. Karate became a structural part of my life. It taught me discipline, patience, responsibility… And how to kick things really hard. Part of the appeal was that I felt like my heroes – doing cool martial arts moves, feeling active and strong. I didn't want to be "normal" like everyone else. I wanted to be better. I wanted to be super.

As I grew older, my love for Superheroes grew, and I eagerly enjoyed watching the world begin to love them just as much as I did. From The Dark Knight Trilogy to The Marvel Cinematic Universe, the thrill and power that had helped me and my family through a challenging growing-up was embraced by the world. At eleven years old, when I watched a meek-but-headstrong Steve Rogers get an experimental transfusion to become Captain America, I

> **"It was something I had grown up avoiding; here was my haemophilia being used as a punchline"**

felt seen. The appeal of these heroes was the push to be the best version of yourself. They set an example of how being smart and being strong could save the world.

Elsewhere in film and TV, the experience was less rewarding. Haemophilia was rarely

mentioned and when it was, it was never in a positive light. In two episodes of the Simpsons, Homer Simpson claims he has haemophilia when injured in order to get attention. One time, he stuck his hand in a paper shredder and, as blood spurted out, he screamed "Ah! My haemophilia!" Another instance saw Bart recounting a fight that Homer was in, saying "Remember when Tom had you in that headlock and you screamed, 'I'm a haemophiliac!' And when he let you go, you kicked him in the back?"

It was something I had grown up avoiding; here was my haemophilia being used as a punchline to portray somebody as weak. A show I enjoyed was using haemophilia to portray a character as pitiful. Doctor Who took a different route, in an episode which featured the royal family as Werewolves (this was an actual plot line!). The Doctor's explanation is that the haemophilia which ran through the royal bloodline was actually a "lycanthropy disease". Instead of haemophilia being something that made someone weak, here it made them monstrous.

Growing up, I had viewed haemophilia as something that made me strong. It was a challenge to overcome and beating it made me feel larger than life and heroic. But in media it was either a punchline or a monstrous deformity. Seeing these portrayals replaced the confidence I had felt from superheroes with a sense of otherness and inferiority. How could I hold my head high in the face of haemophilia when the television shows I most loved told me it made me less?

When I was fifteen, a show called Legends of Tomorrow premiered. It featured a team of super-powered individuals travelling through time to save the world in different periods. It was adventurous, fun, and exciting. Season 2 introduced a new character,

Nate Heywood, who was the one non-powered member on the team. He quickly became my favourite. Nate was an archaeologist who travelled with the superheroes and held his own in fights. He was an everyman who overcame the odds to be just as effective in the adventures as his powered teammates. Midway through his first season, Nate was hurt, and they treated his injuries. As he was being looked-after, another character noticed large bruises on his body.

"I'd recognise bruises like that anywhere," she said. "You're a haemophiliac."

The moment gave me whiplash. Despite the hokey realisation of it, there was something so rewarding about seeing my favourite character in one of my favourite shows – the character who had fought alongside superheroes and saved the world despite his seeming normality – share a disorder with me. Nate also shared my fatal character flaw; he was determined not to be defined by his disorder. He pushed himself harder and took risks to counteract the perception of fragility.

I reflected my own experiences onto him, and the push to prove himself was something I related to. The reveal made me ecstatic. Nate Heywood was a reflection of my experience, my passions, and my identity. It wasn't a perfect portrayal of haemophilia by any means. It used the dated term "haemophiliac" and Nate delivered the maligned urban legend that something as small as a cut could kill him. But the portrayal of a heroic 'haemophiliac' was rewarding, as it felt like a distillation of my experience. I should've known it was too good to be true.

The very episode that Nate discloses his haemophilia, he's mortally wounded. The Legends race him to the infirmary where the clock is ticking to save his life. It felt familiar. The legends realise Nate needs a blood transfusion from his super-powered grandfather to save his life. It's a risky procedure that could kill him but, if it succeeds, he'll gain his grandfather's powers of super-invulnerability. Most notably, his haemophilia would be cured.

The narrative was a perverted portrayal of how I had managed my turbulent childhood in hospitals, condensed into thirty minutes. In the span of two scenes, Nate was cured and was now a superhero. No longer the everyman, Nate wasn't held back by the "burden" of haemophilia. As I watched this episode, I felt a pang of disappointment as it dawned on me; Nate's haemophilia wasn't his superpower... It was his Kryptonite.

I stopped watching Legends of Tomorrow after season 3. The appeal of watching superheroes was numbed when I realised shows like this saw them as an unobtainable standard. You weren't supposed to see yourself in these characters, you were supposed to worship them. And they were bigger and better than anything I could ever accomplish.

As I grew older, moving through the final years of high school and then into university, I saw my haemophilia reflected positively in a different way; reality. I saw those with haemophilia - both people I knew and people circulating through the community - achieve extraordinary things.

> ***"support of the ABDR by patients entering treatment and bleed data will be important to continue access to treatment"***

Chris Bombadier famously climbed Mount Everest - a feat that could only be described as superhuman.

Others chased careers at one point considered unobtainable for people with haemophila. They went on international adventures, and hit physical peaks in the gym that even people with perfectly high factor levels would be incredibly envious of. In my own friends and peers, I see the reflection of that motivation and drive that growing up with haemophilia instilled in me. Those of us that grew up with haemophilia understood something that the media never did - it wasn't a curse, or an excuse to use to hold us back, or something that stopped us from being super... It was a *challenge*, a push to make every decision and accomplishment that much more earned. Everything we did, we did with haemophilia. And that made it all the more unbelievable.

As I write this, I am on the cusp of receiving a life-changing gene therapy treatment that would effectively bring my factor levels to normal. The irony (that this isn't too far from what happened in the fantastical work of Legends of Tomorrow) isn't lost on me. However, I will never forget or disregard the challenges haemophilia has brought me and the lessons it has taught me.

Life with haemophilia can be like running with weights on your legs. You occasionally move slower, you push harder, and you sometimes have to stop unavoidably. Anyone who lives with haemophilia and manages to keep up with their peers should be incredibly proud. You have had to work just that bit harder. But when that weight lifts, you can damn-near fly.

ONE COMMUNITY, MANY FACES

Bleeding Disorders Awareness Month

OCTOBER 2022

As you may know, this year in October we will have a whole month to raise awareness about bleeding disorders.

The 2022 theme for Bleeding Disorders Awareness Month is **ONE COMMUNITY, MANY FACES**. Each week we have different topics and will meet community members from all ages and stages of life to hear their stories.

ACTIVITIES AND EVENTS – BOTH VIRTUAL AND FACE 2 FACE

We will launch our calendar at the end of September. To be advised about events, register for our E-news www.haemophilia.org.au/enews or keep an eye on our website and social media platforms.

PROMOTIONAL ITEMS

Promotional items orders are now open. Order the free goods to use for your school, workplace or family/friend event. We have balloons, pens, Fling Things (like a frisbee), colouring-in sheets, information posters and lots more.

Put your order in at
www.haemophilia.org.au/BDAMorder

HOW CAN YOU BE PART OF THE WEEK?

- Order promotional items for your event, information stalls and your child's school/child care
- Run a virtual or face-to-face fundraising event
- Host a red cake day
- Share information on your social networks
- Share your story - https://tinyurl.com/HFA-story
- Children and their friends can take part in the colouring-in competition or a Scavenger Hunt
- Take part in HFA and Foundation activities (Calendar coming soon)

For more information, contact
Natashia Coco
MB: 0403 538 109
E: ncoco@haemophilia.org.au

WORD FIND

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

Bleed	Bruise	Factor
Haemophilia	Hereditary	Joint
Mild	Moderate	Port
Severe	Treatment	Vein
VWD		

Answer sheet available to download at www.haemophilia.org.au

GLOSSARY

BLEED – In haemophilia, bleeding episodes usually occur inside the body, with bleeding in muscles and joints, such as ankles, knees and elbows

BRUISE – An injury causes tiny blood vessels called capillaries to burst. Blood gets trapped below the skin's surface, which causes a bruise

FACTOR - A blood plasma protein that is an agent in the clotting process

HAEMOPHILIA – An inherited bleeding disorder where the blood doesn't clot properly. It is caused when blood does not have enough clotting factor

HEREDITARY – Passed in the genes from parent to child

JOINT – The place where two or more bones come together

MILD – 5% – 40% of normal clotting factor level - the severity of haemophilia depends on the amount of clotting factor in their blood.

MODERATE – 1% – 5% of normal clotting factor level - the severity of haemophilia depends on the amount of clotting factor in their blood.

PORT – A device put under the skin to give easy access to a vein for treatment and to protect veins from continued needle sticks.

SEVERE - Less than 1% of normal clotting factor level - the severity of haemophilia depends on the amount of clotting factor in their blood.

TREATMENT – Medical care given to a patient for an illness or injury

VEIN – Blood vessel which carries blood from any part of the body back to the heart

VWD – People with VWD have a problem with a protein in their blood called von Willebrand factor (VWF) that helps control bleeding. They do not have enough VWF or it doesn't work properly, and it takes longer for blood to clot and bleeding stop

Haemophilia Foundation Australia
P: 03 9885 7800
E: hfaust@haemophilia.org.au
W: www.haemophilia.org.au

HAEMOPHILIA FOUNDATION AUSTRALIA

Ask Us: Alfred Health Patient Portal

Jane Portnoy and Alex Coombs

Dear Ask Us,

I have many appointments both at the Alfred and elsewhere. Occasionally I miss an appointment.

Hi there,

Have you heard of the Alfred Health Patient Portal?

To access the patient portal, you will need to individually register, even if more than one member of your household is an Alfred patient (i.e., husband, wife, adult siblings, etc).

The patient portal will enable you to:

- View your upcoming appointments
- View your pathology results from tests conducted at the Alfred Health pathology laboratory (14 days after a final result has been determined), excluding anatomical pathology and genetic testing
- View letters that have been sent to you and/or external providers
- View your inpatient discharge summaries from any unit
- Receive secure messages from your healthcare team
- You can book in for blood collection, which is great if that is the main reason that you are attending the hospital, as it helps to avoid long waiting times

Please follow the link below:

alfredhealth.org.au/patients-families-friends/patient-portal

The aim is to give you a bit more control and a handy aspect of the portal is that it's easy to check on your appointments to avoid a missed appointment! It is also easy to cancel or change appointments.

As always, this information is protected by the Alfred IT security system, so please do not give out your registration details to others. Keep these private and not in easily obvious places.

Take care,
Alex & Jane
Social Workers
Ronald Sawers Haemophilia Treatment Centre

Alex Coombs and Jane Portnoy are Social Workers at the Ronald Sawers Haemophilia Centre at Alfred Health. This article was written for "The Missing Factor," 2022.

A Family Coincidence at the Alfred

Dr Ronald Sawers is a well-known name in the Victorian bleeding disorders community. It was Dr Sawers who first encouraged a group of parents to form The Haemophilia Society of Victoria (Haemophilia Foundation Victoria's previous name), and provided the organisation with valuable medical advise up until 1984.

Of course, Dr Sawers' other claim to fame is the *Ronald Sawers Haemophilia Centre* (RSHC) at Alfred Health - one of Victoria's two Haemophilia Treatment Centres. A happy coincidence occurred recently when Tony Sawers (pictured below) noticed the name of his "Uncle Ron" at the RSHC as he was passing.

Tony, the haematologist's great nephew, walked in to find out more. Upon learning about Tony's relationship with Dr Sawers, the RSHC team quickly grabbed a picture of him standing alongside his great uncle's career highlights poster. After a brief and educational chat, Tony went on his way, leaving the team with a new nugget of family knowledge... It turns out Dr Ronald Sawers was a twin!

Tony saw his great uncle Ron's name at the Alfred and went in to find out more.

World Hepatitis Day 2022

World Hepatitis Day is marked globally on 28 July. This is part of a worldwide campaign to eliminate viral hepatitis by 2030. In 2022 the theme is hep can't wait, reminding us that we need to be proactive in our efforts.

Hepatitis C has had a profound effect on our community. In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

HEP CAN'T WAIT!

TAKING ACTION

Highly effective hep C treatments are available in Australia. They are easy to take - one tablet a day, not injections - with cure rates above 95% and few if any side effects.

WHO IS AT RISK?

If you had clotting factor or a blood transfusion before 1993, you could be at risk for hepatitis C.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some might not even know they have hep C. You may have had very few treatments in your lifetime and never thought you would be at risk for hep C. If this is you, don't wait. Talk to your doctor about being tested – find out if you have hep C. Testing and treatment is simple. Hep C can be cured.

WERE YOU CURED OF HEP C?

Did you have liver damage or cirrhosis?
Has your liver recovered from hep C? Don't wait to find out.
Call your hepatitis doctor or your GP to check your liver test results.

Find out whether you need ongoing follow-up with a liver specialist.

REMEMBER...

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

KEEP YOUR LIVER HEALTHY

Have a balanced diet, maintain a healthy weight, and avoid or minimise alcohol intake.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research is continuing into new and improved hep C treatments and management of advanced liver disease.

MORE INFORMATION

For more information, visit:
- www.world.hepatitisday.org.au
- or the HFA World Hepatitis Day page at www.haemophilia.org.au/world-hep-day

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

RECONNECTING WITH THE COMMUNITY POST COVID

Shauna Adams

I was fortunate to have the opportunity to attend the WFH world congress in Montreal in May. I was excited to attend my first congress, but it was also wonderful to meet and catch up with people face to face for the first time in some months. It was interesting to hear about how National Member Organisations (NMO)'s around the world stayed connected during the pandemic, and some of the challenges they faced. Everyone is now very fluent in Zoom, and it was great to see the positive spin on things experienced by a lot of the community.

Most local groups moved to a complete remote delivery of their gatherings and meetings for some time, slowly transitioning into mixed mode delivery as social distancing requirements allow. The congress itself was delivered in a mixed mode platform, and while this allowed people to attend who may have been impacted by COVID restrictions, it also meant that people who may have been financially restricted or not physically able to attend could also be involved in the congress.

WFH reported that they have been able to increase the delivery of training packages to NO's around the world, which has been hugely beneficial to remote countries who are generally not able to attend on location training sessions. This has resulted in a review of the ongoing delivery methods used so that we can continue to reach the wider global community in future.

In the medical delivery space, several countries moved to telehealth for ongoing care of patients with bleeding disorders. NMO's in the US reported that patient satisfaction surveys indicated over 70% of patients were satisfied with this method of care. Surveys also indicated that telehealth was more readily adopted by the younger cohort of patients.

Where local groups have shown great success in moving to virtual activities, some of the global initiatives saw a decline in attendance as time zone differences became a challenge. The affirm program found countries with time zones that were drastically different from the host country to have a higher dropout rate.

It was great to see the creative ways our community have kept in touch on a social level in the face of adversity. The Pakistan Haemophilia group conducted youth events as joint online gaming sessions in the absence of usual youth camps. A lot of NMO's reported zoom catch ups socially too.

> ***"Everyone is now very fluent in Zoom, and it was great to see the positive spin on things experienced by a lot of the community.***

This article was first published in "Activated: Newsletter of Haemophilia Foundation Australian Capital Territory" in August 2022. The article was adapted by Haemophilia Foundation Victoria, and reprinted with permission.

THE CHANGE IN THE HAEMOPHILIA TREATMENT CENTRE OVER THE LAST 20 YEARS

By Julia Ekert from the Royal Children's Hospital Melbourne

When I started work in the Haemophilia Treatment Centre in 1997, my job was quite different to what it is today. Our haemophilia database was a very basic Access database which recorded the demographics of our patients and not much more. Now we have the ABDR and MyABDR which collects so much more information to help in the management of patients with bleeding disorders. The main part of my job at that time was to call the Red Cross blood service on a daily basis to order plasma-derived factor VIII for our families to use as their prophylaxis product. Recombinant factor VIII was not available to everyone at that stage. Professor Ekert was the director of the treatment centre and he advocated strongly for the availability of recombinant factor product for all children with haemophilia. With his support (and with Dr Barnes and the haemophilia team in later years), there has been so many changes in the Haemophilia Treatment Centre.

Families used to have to come to the Royal Children's Hospital (RCH) to collect their Recombinant factor VIII and IX as well as picking up their treatment equipment that they required to use for an infusaport or give IV treatment. This equipment includes things like Huber point needles, sterile gloves, sterile packs syringes etc. Prior to 2002, haemophilia families had to pay for this equipment, which could cost up to $200 a month. In 2002, the haemophilia equipment fund (which is funded by the state government) was introduced after lobbying from the haemophilia community, including the families and HFV. With this funding came the management of the fund by the HTC. As part of the management, we track equipment

use each year and prepare a budget statement to the Department of Human Services for it to continue each year.

As Recombinant factor VIII and IX became the standard of treatment for haemophilia, the National Blood Authority (NBA) was also established in 2002 as the body to run the tendering process for Clotting factor products and to ensure an adequate supply of these medications for all patients. Prior to the NBA, there were 3 companies who had TGA approval for Recombinant factor VIII in Australia and it was up to the hospitals to decide which factor VIII they bought. There was only one recombinant factor IX at this stage. At the RCH we bought from all three suppliers as it was thought that it would keep them all in the market and help to ensure supply. There was no home delivery at this point, so families would call to place their order with the HTC. This involved leaving a message on the phone and letting us know how much factor had been used in the last month. There was no online recording at this time, so this was an important step in knowing what was being used and whether patients were having bleeds, etc. Once the order was placed, the family had to come to the hospital to pick up their monthly supply of clotting factor and equipment. Because clotting factor was not assigned to specific patients, they could get any one of the three different clotting factors at collection. Before the NBA was established, each state would fund the clotting factor products. This meant that the HTC had to predict how much clotting factor they would use in the next year and submit a budget to DHHS. This was always a difficult process because we were asked to predict bleeds and inhibitor development.

In 2006, the NBA included home delivery as part of the national tender. This was a big change to the way families received their home treatment supply. In order to work out a process for home delivery, the RCH introduced home delivery to a small number of patients and then surveyed them to see how it was working. We asked things like "For how long was it acceptable for the pharmaceutical company to call and do a stock check?" "What was their preferred method of contact - SMS or email?", "Is it more convenient picking up at the hospital?", "Were there any improvements that could be made?" The results were overwhelmingly in favor of home delivery. This was a major step forward for the haemophilia patients. The introduction of home delivery again changed the job of the HTC team introducing a lot of

new processes and check and balances to ensure families got the right stock.

In 2008, the NBA funded the Australian Bleeding Disorders Database (ABDR). This meant that our local Access database became a national internet-based database. The new ABDR also included clinical information so, for the first time, we were able to enter clinical data such as treatments, pathology tests, surgery details, etc. The ABDR also served to inform the NBA how much clotting factor was being used. This, in turn, helped them to predict what Australia would require in the future and inform them during the tender process for clotting factors. This again changed my job, and I not only ran the home delivery program but also became responsible for updating the ABDR both clinically and inputting the clotting factor usage data. The NBA expects that the clotting factor data is updated to within a three-month period. Each year the data need to be complete by the end of September so that the NBA can write their annual report.

MyABDR was launched in 2014. This has been an amazing tool for the HTC. It helped us to track what treatment product our patients have at home and helps to make the job of ordering products for the families much easier. With the event of Hemlibra, MyABDR has become even more important. Not only are we managing Hemlibra stocks, but we are also managing factor VIII stock kept at home in case of emergency. This is important as it informs our advice about treatment if a patient has a bleed. Having the inventory up to date with batch number and use-by dates is vital.

In 2018, the NBA introduced an interim program to swap from short-acting factor VIII and IX to long-acting factor VIII and IX. The initial program allowed for 200 patients in Australia to be swapped – 60 haemophilia B patients and 140 haemophilia A patients. Given that it was an interim program, not all of our patients qualified. In order to swap in patients who qualified, we needed to see them in a clinic visit face-to-face to demonstrate the new product and provide education on new doses. This swap started 2018 and in July 2020, extended half-life product became available for everyone under the new NBA tender agreement. We were then able to offer this to all our patients and continue the roll out – albeit now utilising telehealth as we were also dealing with COVID.

At the end of 2020, the NBA announced that it was going to fund Hemlibra for all severe and moderate haemophila A patients. This was amazing news and was going to change the face of haemophilia. It also meant we had to design another program to roll out Hemlibra to our community. This meant that we again needed a face-to-face teaching program with the families – plus we had to add COVID issues into the mix. The RCH was encouraging us to do all appointments via telehealth, but we needed to see the patient face-to-face in order to teach them how to give a sub-cut injection. Given that nearly all our patients are now on Hemlibra, this obviously worked – but it was not without some stresses.

I have been lucky to work in the Haemophilia Treatment Centre during so many changes and it has been a real privilege to see how the changes in treatment have resulted in improved care for the patients at the Royal Children's Hospital. Like many aspects of health care, data management has become increasingly important. I have enjoyed working with the families to make sure that the data is accurate, and that it supports ongoing access to these amazing products.

Julia Ekert is the Data Manager at the Henry Ekert Haemophilia Treatment Centre at the Royal Children's Hospital Melbourne. This article was written for "The Missing Factor," 2022.

Upcoming General Meetings

SPECIAL GENERAL MEETING - ACCOUNTING

A Special General Meeting of Haemophilia Foundation Victoria Inc. will be held on **Wednesday 5th October 2022**, commencing 7pm on Zoom

Edwards Pearl & Co, the auditors appointed by members at the 2021 HFV Annual General Meeting to conduct the annual audit of the foundation for the 2022 Financial Year, recently advised Haemophilia Foundation Committee of Management that they are no longer able to conduct the audit. Accordingly, new auditors need to be appointed immediately.

Please see the enclosed Letter of Notice of Special General Meeting for further details.

2022 ANNUAL GENERAL MEETING

2022 has flown by and it's almost time for the HFV Annual General Meeting.

The 69th Annual General Meeting of Haemophilia Foundation Victoria Inc (HFV) will be held as a virtual zoom meeting. The meeting will take place on **Wednesday 23rd November 2022,** commencing 7pm on Zoom.

Special Event: Following the close of official AGM business HFV is delighted to announce a special Q&A Virtual Panel session featuring a number of HFV members who will be sharing their personal stories with us.
You will also have an opportunity to socialize and chat following the panel.

Please see the attatched Letter of Notice of Annual General Meeting for further details.

Notices & Information

IT'S TIME TO RENEW YOUR HFV MEMBERSHIP

With the new financial year in full swing, it is time to renew your HFV membership if you have not done so already.

Scan or click the QR code for a digital copy of the membership renewal form. This can be filled out using your phone, computer, tablet, or by printing.

If you require a physical membership renewal form, or need to update your address in our database, please let our office know as soon as possible. Our contact details are on p.23.

We look forward to another year in service of this wonderful community.

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

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**

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
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 opportunties 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.

HFV SPRING DIARY DATES 2022

Wednesday 21 September 12:00pm	Incredible Race for Teens 13-19	Melbourne CBD	Bookings close 19 September 5:00pm
Sunday 2 October TRARALGON 10:30am – 12:00pm WARRAGUL 2:00pm – 3:30pm	Gippsland Regional Visits	Traralgon: Frankie's Cafe Warragul: Newmason	
Wednesday 5 October 7:00pm	HFV Special General Meeting (RE audit)	Zoom	Bookings open 19 September
Saturday 8 October 10:30am	Bleeding Disorders Awareness Walk	Albert Park Lake	Bookings open 19 September
Wednesday 23 November 7:00pm	Annual General Meeting	Zoom	Bookings open 19 September