

AUTUMN 2022

THE MISSING FACTOR

connect • support • empower

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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

PRESIDENT'S REPORT

Welcome to 2022!

A new year and a new chapter at HFV. No doubt you will have noticed the new look of the newsletter and that is because we have welcomed Yarrow Ruane to the team. Yarrow has filled the very big gap left when we lost Julia last year. Yarrow has hit the ground running and bringing a breadth of skills and new ideas to the work at HFV. We welcome Yarrow and look forward to working together.

At the committee we have also had a few changes. Fortunately many of the committee have stayed for another term but we also welcome back a few familiar and much loved faces with Zev and Ben returning. Our committee reflects the diversity of our community with a mix of youth and experience, parents and people living with a bleeding disorder as well as metro and rural. A great mix of ideas and passion. However we do have a few spaces so it is never too late to be involved. The committee is hoping to gather in a few weeks to revisit our strategic plan and map the future look for programs and events. We always welcome the ideas from our community as you are our members so please feel free to share your thoughts.

As we all start to venture outside our doors into the post COVID life we hope to enjoy we are hopeful in our plans to return to face-to-face community engagement. Like most of us I am tired of seeing a face on a screen and can't wait for community camp in May. Camp will be fantastic and a time to meet new and familiar friends as well as meet Yarrow, Andrea and the committee. (We are also hopeful there may be some from other states to join us but still early days) Similarly I know many of our men are also looking forward to the retreat and an opportunity to

reconnect with mates.

The past few years have been challenging for us all as we know but for some it has been a very lonely time indeed. Many of us are still hesitant to venture outdoors and we all need to make the right decisions for ourselves and our families. HFV will do all we can to provide a safe environment for our events as well as follow all guidelines of government. If you are unsure or feel you need a little guidance please reach out to those that are here to support your decision making. Our HTC's, our staff and our community are all here to support all our members in the road that is ahead so as always remember we are an email or phone call away.

With the sadness of the floods up north we think of our foundation friends at HFNSW and HFQ and hope all their communities stay safe and supported. With the images from Ukraine we are also left with a sense of helplessness. COVID may be a bit different now but still a big part of our lives as well. As we all try to make sense of 2022 and what it will mean to so many that are struggling we at HFV just want to reassure you our doors are open (even if virtual still) We are open for business and here for you and your family and loved ones.

Enjoy the newsletter! It is well worth making a cuppa and relaxing without a screen in sight.

Be safe and hope to see you soon.



Leonie Demos HFV President



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

A CHANGING TREATMENT LANDSCAPE

By Dr Chris Barnes from the Royal Children's Hospital Melbourne HTC

The treatment landscape of haemophilia has dramatically changed over the last 20 years. Treatment in 2022 is associated with reduced bleeding risk and reduced treatment morbidity. Non factor therapies offer the ability to prevent bleeding events without the need for regular intravenous infusions. This provides the chance for parents of infants born with haemophilia in 2022 to expect that their young child can have a near normal quality of life; a life with few, if any restrictions.

It is important to acknowledge that this change in the treatment landscape has only been possible with the widespread engagement of all of stakeholders in the haemophilia community; including patients, patients' families, haemophilia treatment centres, industry partners and government. Haemophilia Foundation Australia and



the state based haemophilia foundations a pivotal role in advocating for improved treatment for patients with haemophilia. It is widely acknowledged, amongst all health care professionals within the haemophilia community, that the current excellent treatments would not be available if it were not for the persistent, focused advocacy of the HFA staff.

“patients are needing additional education and support in identifying and managing bleeding events in the era of non-clotting product”

With the change in the treatment landscape, it is expected that haemophilia treatment centres will also change. There is a potential for patients to have less contact with haemophilia treatment centre staff. Haemophilia treatment centres are staffed by small numbers of highly specialised dedicated nursing, physiotherapy, social work and medical staff and are supported by engaged and highly effective data management professionals. The change in the treatment landscape to subcutaneous therapy may lead to less need for young patients to have central lines and less need for patients and patients' families to learn intravenous techniques. Support for patients to have home based therapy with home delivery of clotting products is likely to be less common.

It is likely that patients will still experience bleeding episodes. Based on published research and supported by our increasing experience with the subcutaneous treatment, these episodes will be less frequent and potentially less severe. Treatment with clotting factor may be required however, due to the infrequent need to treat bleeding events, patients may be less comfortable treating the bleeding event at home. They may need to attend treatment centres or emergency departments to have clotting factor infused. HTC staff are monitoring how best to support patients with the initial management and where and how this treatment can be best provided. It is possible patients may need to come to a treatment centre for acute management or need to be fast tracked through emergency departments. Education of emer-

gency department staff may need to be addressed to support efficient treatment of acute bleeding events.

Rehabilitation and physiotherapy remains essential to ensure return to optimise function following bleeding events. Our expert physiotherapy staff are considering how best to provide this treatment and it is likely treatment centre-based management will be required for these infrequent bleeding events. Our experience suggests patients are needing additional education and support in identifying and managing bleeding events in the era of non-clotting product therapies. Australia is fortunate to have musculoskeletal professionals

“support of the ABDR by patients entering treatment and bleed data will be important to continue access to treatment”



expert in the management of patients with bleeding disorders and their ongoing input will be important to optimise the effectiveness of the new treatments.

Haemophilia treatment centres may have necessarily focused on patients with severe bleeding disorders. The reduced treatment burden of managing patients

with severe haemophilia (including patients with inhibitors) now provides an opportunity to focus on patients with less severe clinical phenotypes. It is widely acknowledged patients with mild and moderate bleeding disorders may still have significant morbidity associated with their bleeding symptoms or adjustment to living with a bleeding disorder.

Data management is critical in healthcare. Engaging patients in providing treatment data in real time can be a challenge. Australia is very fortunate to have a dedicated patient focused treatment registry with the Australian Bleeding Disorders Registry. Support for the ABDR is provided by federal and state governments and the data collected has been instrumental in ensuring access to the current treatments. Ongoing support of the ABDR by patients entering treatment and bleed data will be important to continue access to treatment.



“Nothing is more constant than change”. This quote adequately captures haemophilia treatment over the last few decades. The haemophilia community, supported by HFA, is fortunate to have access to extraordinary life changing treatments. These treatments offer different challenges for the haemophilia community. It is essential that haemophilia treatment centres adapt to these changes.

TALKING TREATMENT CHANGES

with HFV Members



Disclaimer: Emicizumab (brand name Hemlibra) is currently the only nonfactor-replacement therapy licenced to treat haemophilia in Australia. HFV anticipate new treatments being made available and supports the development of research into all effective treatment products. We encourage people with bleeding disorders to make informed decisions about their own treatment, under the advice of their HTC. This article aims to share the lived experiences of several HFV members. HFV does not endorse or favour any one treatment product.

“It’s the first time in 53 years that I haven’t had to worry about my life being interrupted.”

Martin has severe haemophilia A. He switched treatments over a year ago.

Born with severe haemophilia A in 1968, Martin describes his history of treatments and injuries as being rather long. He remembers the personal significance of each change in treatments - first, moving to on-demand home infusions in year 8, and then starting prophylaxis 12 years ago. More recently, Martin switched to a new type of treatment product.

“Once a year, I find it helpful to catch up with peers through the Men’s Retreat. We tend to swap stories about disastrous bleeds, treatments and everything else.” It was at one of these events, after sharing his experiences with a recent breakthrough bleed, that Martin first heard about others’ success with nonfactor therapy. At his next meeting with the Alfred, Martin asked to switch.

“It’s the first time in 53 years,” Martin says, “that I haven’t had to worry about my life being interrupted.” More than a year after changing treatments, he is feeling “really positive”. In particular, he was glad to see a decrease in the number of “background bleeds” that he gets. “I can do some light exercise with weights, play my guitar, lift my kids, go for a swim - all these things used to be associated with a little bit of bleeding.”

For Martin, however, “bleeds are only one part of living with the condition”. Changing treatments, he says, “doesn’t change who you are. You’re still going to have plenty of stuff to worry about, but now my life is a lot easier to manage.” These days, Martin worries less about his venous health, and works his subcutaneous injections into his workday. “No regrets at all,” he says, “it really has been lifechanging.”



Paddy is 20 years old and has severe haemophilia A. He switched treatments 2 months ago.

When he was at the Children’s, Paddy was always hearing about new treatments. After moving to the Alfred about a year ago, he started thinking about his options. “I thought about doing a gene therapy trial. It seemed like it could be pretty lifechanging, but I’d have to go in every week, and I wasn’t sure how I’d fit that into my schedule. I ended up being put on the waitlist for Hemlibra.”

After COVID restrictions eased, the process started to speed up. “I was Googling every little thing about Hemlibra,” Paddy said, “I’m probably not always

as careful as I should be, so I was nervous about having low factor levels.” But he liked the idea of more consistent factor levels and wanted to administer treatments less often.

The lead-up was nerve-wracking. “I was pretty nervous to switch to subcutaneous injections, especially because I was always good at finding my veins. The first time I did it [through the skin], I was in the hospital and my hands were shaking - it took way longer than it needed to! I’ve gotten much faster since then.”

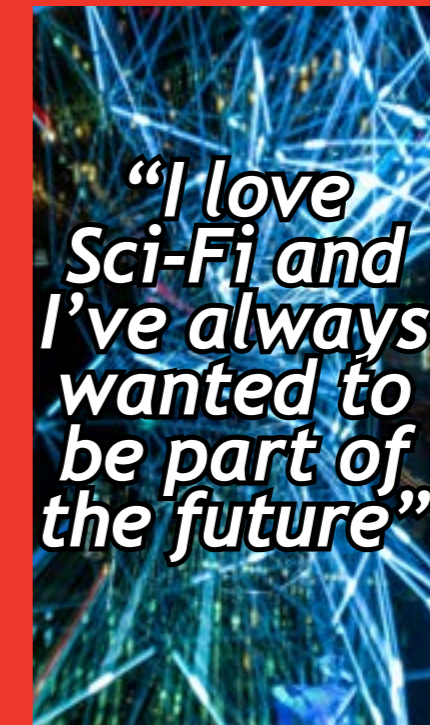
About a week later, Paddy reached the most stressful part of the process - he stopped administering factor. But, Paddy said, things have gone well so far. “This opportunity has been pretty lifechanging, to be honest. I know that I can do it once a week and forget about it. When it comes to minor day-to-day things, I just don’t have to think about them.”

Mike has severe haemophilia A. He switched treatments 12 months ago.

Three times a week for the last 35 years, Mike took Factor XIII. But in early 2021, after a briefing from the Alfred, he decided to switch to nonfactor therapy. Looking back, Mike said “it was the best decision I made all year.” In fact, Mike considered himself “a believer from the very start. I love Sci-Fi and I’ve always wanted to be part of the future.”

Having now been on nonfactor therapy for a year, Mike has found four main advantages to changing treatments. “It’s been more effective at preventing bleeds, needs to be taken less often, is far easier to administer, and does less damage to my veins!” That last point was particularly important for Mike, who had previously had scar tissue interfere with venous access.

Mike’s factor levels were put to the test last year, when he was involved in a serious scooter accident.



While he walked away with several broken bones and extensive bruising, Mike was surprised to learn that he had not experienced any serious joint bleeds - a fact that he attributes to his prophylaxis.

Mike has now settled into his new treatment routine. “I just pick it up from my local pharmacy every month and administer it once a week. Half the time, I can’t even feel the needle.” Reflecting on his experiences with both the new treatment and its HTC administrators, Mike said, “I can’t believe how blessed I am. I feel so privileged to be living in Australia.”

This article was written by Yarrow Ruane, Communications Officer at HFV. HFV are also interested in hearing about treatment changes from other perspectives. In particular, we would love to hear from some of our members who have inhibitors. To contribute to a future newsletter, please contact yarrow@hfv.org.au.

Thank you to Martin, Mike and Paddy for your contributions.

Your Body in a Pandemic

By Abi Polus

With the various restrictions and resultant ongoing changes in our ways of living these days, many people have reported that they are using their bodies in a different way. Working from home, closure of regular facilities and different demands on time have all impacted the amount and way that we are moving, both positively and negatively. This article addresses some of the common changes that have been reported to us by many, and what we have observed. Of course everyone will have individual changes and requirements, and we encourage you to talk to your musculoskeletal team at your HTC for assessment, advice and information specific to you and your needs.

◆ WORKING & SCHOOLING FROM HOME

This remains a reality for many people and like everything, has both pros and cons. What many people have reported from a physical perspective is the lack of incidental exercise that they get from attending their workplace, both going to and from work or school (even if it is just a walk to the car and from the car park or public transport). Similarly moving to different areas or sites as they would at a workplace, playtime and scheduled sports at school, going to get grab a coffee or get lunch, or attend a meeting in a separate area. Often at home during work hours we may tend to stay in a more enclosed space, coffee and food may be more readily available, and we may be able to interact with (or hide from) others from a seat in our personal homes or somewhere else online.

Regular activity breaks that incorporate movement can be extremely beneficial. Examples may include walking meetings, in person or via telephone calls or tele-platforms, walking to a coffee shop or park during breaks in meetings or work, answering the need for the caffeine fix or hunger pangs outside of your kitchen, or just to increase your activity. Dance breaks are commonly used in online schools but anyone can crank up a favourite song every few hours, doing an impromptu (or choreographed!) dance routine is beneficial for muscles, joints, endorphin levels (happy hormones) and having fun. Extra points if it leaves you breathless- do the whole song- cardiovascular training!

◆ WORKSPACE

This may be a different set up at home than at the office. Whilst the initial 'making do' for a few

weeks may become more permanent and then 'few more weeks' has transitioned into months, it may be worth investing some time, energy and finance into having a good workspace. Wherever you work, it should be well set-up with you being able to work without eye, neck or arm strain, or any other neuro-musculoskeletal stressors. Some companies will help with home workplaces, others less so.

Ask someone else to take a sneaky (by that- agreed to before hand- but unaware when!) photo of you at your workstation to look at your posture/ setup - is it what you think it should be? It IS usually worth fixing it up, as chances are you will use it again and musculoskeletal pain, potential of increased bleeds, and issues from poorly set up spaces is something that can be avoided.

◆ EATING

We have scientific evidence and individual reports that an increase in fat cells can increase inflammatory pain, and that increased weight on a joint that has been previously bled into can cause pain. Being conscious of your weight and body composition, and what you are eating is important, particularly if you are doing less activity.

Habits of eating when sitting at a device or during other sedentary activity may be ingrained, and eating for boredom with easy access to food may also come into play. The advice here is to examine you eating practices and identify patterns, and make modifications if you need to.

◆ EXERCISING & ACTIVITIES

With some gyms and pools still closed or with restricted access, it can be so frustrating not to be

ABI'S TOP TIPS FOR STAYING MOTIVATED



Count Your Steps

Can be a fancy watch, can be on your phone (iphone/android has this feature on many free apps): Look what a 'normal' day for you is and then try and increase it- incrementally- until you are at an achievable goal.



Track Yourself

Keep an activity chart/diary for motivation if you are someone who benefits from this type of motivation. Again apple/android have lots of free apps for this, or go old-school with a calendar or tick chart.



Do What You Enjoy

Sounds obvious - do an activity you enjoy rather than what you feel you should. If you hate it you are less likely to do it. But do something.



Make it a Group Activity

Having a friend or colleague can keep you motivated or challenged; have a school/workplace physical activity competition or have a dance off with your mates between meetings.

able to return to what we love and know works for us. We may need to engage in activities less efficient or enjoyable in the short term; the big message here is don't do nothing, do something. Keeping active is essential for joint health and muscle protection of joints vulnerable to bleeds. Regular walking or activity is necessary, in the interim, with the idea that returning to the activities you enjoy and that are best for you when you are able.

When we do return it can be really frustrating not to be able to return to the levels that we were at previously. I would urge caution here and go slowly to work toward the goals and targets you were previously hitting. In order to avoid a bleed or musculoskeletal strain or

injury or nasty DOMS (delayed onset muscle soreness) because your body isn't quite up to what it was when you last undertook and activity graduated increase is essential. As a rule of thumb waiting 48 hours after each increase and seeing how your body responds to the demands placed on it is a good way to start.

◆ CHANGING PRODUCT

During COVID many patients have changed or modified their prophylactic regime for a number of reasons. Weight changes during lockdown may change dosages, and product changeover for many has corresponded to the onset of COVID restrictions. What you may have been able or unable to do on one product at a certain dose may not

be the same as what you can do on a different program. Again, slow and steady increase is recommended.

◆ MENTAL HEALTH

This has been recorded globally as changing. There is much evidence of the link between musculoskeletal health and mental health, although clearly in a pandemic other factors are at play. Contacting a health professional for advice is the route to best care, and any healthcare professional can guide you and suggest the best person/people to help you if it is not their speciality are. Please, do reach out for help.

Abi Polus is a Physiotherapist with the Alfred HTC Team

WHY DO WE NEED A GP IN THE TWENTY-FIRST CENTURY?

Alex Coombs from the Alfred
answers your questions about
GPs & bleeding disorders

WHAT CARE DOES THE HAEMOPHILIA TREATMENT CENTRE PROVIDE?

- Specialist focused bleeding disorder clinics
- A monthly Multi-Disciplinary Team (MDT) clinic consisting of Haemophilia, Rheumatology, Pain Specialist Services, HTC Nurse Consultants, Physiotherapy & Social Work
- A monthly Rheumatology focused clinic
- Musculoskeletal Physiotherapists sessions are available over the five day working week by appointment
- Social Work services continue to be available five days a week

WHAT ARE SOME TYPICAL SERVICES PROVIDED BY YOUR GP?

- “Diagnosing and treating disease, pain and other conditions
- Vaccinations
- Mental health advice
- Family planning advice
- Wound care
- Prescribing medication
- Writing referrals for tests or scans
- Referring you to specialists.”

-BetterHealth Channel

Those with long memories will recall the days of your Ronald Sawes Haemophilia Treatment Centre (or HTC) being a “one stop shop” for a variety of health problems. The Alfred HTC one stop shop previously was the place you may have come to request completion of a medical summary for a variety of government or work place application forms. Such documents such as Centrelink medical summaries, including Disability Support (DSP), Unemployed (now known as Jobseeker) temporary sick leave, Disability Parking Permits, Office of Housing Medical Priority Forms were left for your haematologist to complete. Add to this now the National Disability Insurance Scheme (NDIS) forms that is becoming common for many.

However, this is no longer sustainable and hasn’t been for many years the practice. What has been increasingly obvious is that health issues outside the HTC specialist service will continue for everyone as we all age, through injury or accident at home or in the work place.

We have and will continue to now redirect you to see your General Practitioner (GP) for these purposes and for general health matters.

Over the years your HTC has had to make changes to keep up with the increased number of patients that are registered with the centre. This includes those with varying inherited genetic bleeding disorders and acquired bleeding disorders.

Building a relationship with a local GP who is kept informed about your medical history, is the recommended primary contact point for helping you to apply for and complete the medical documentation required. This will enable the Alfred HTC to focus on the care, coordination, education, and treatment of our patients with a bleeding disorder.

WHAT CAN THE GP DO FOR ME?

You are always encouraged to contact the HTC for advice, and particularly when you think that it is related to your bleeding disorder. However there are many times your GP should be your first point of contact for non-emergency and preventative medical care. Throughout

“It is essential that you select a GP who you feel comfortable talking to about the difficult or complex parts of your health.”

your lifespan you may find routine medical check-ups will benefit you by keeping up to date on your overall health status. GP services are in high demand in certain geographical locals. They are experts in managing your general health. Your chosen GP is encouraged to call the HTC for advice if they have any doubts or questions in regard to your bleeding disorder or they suspect the presenting issue may be related to your bleeding disorder.

“GPs are trained in medicine and are qualified to treat people for general health

“Over the years, your HTC has had to make changes to keep up with the increased number of patients that are registered with the centre.”

problems, such as illnesses or injuries that cannot be treated by over-the-counter medication. Some GPs also specialise in particular areas, such as children’s health, mental health or aged care for example.” (Better Health Channel)

It is essential that you select a GP who you feel comfortable talking to about the difficult or complex parts of your health. You may base your choice upon the recommendation from others, the GP’s gender (if you feel that they will be more sympathetic or empa-

thetic towards you), or from your ethnic/cultural/language group. Alternatively you may visit multiple GPs in your local area until have chosen one who you are comfortable with, maybe even one medical centre with several GPs to choose from, till you find the best person to coordinate your overall healthcare. Once you have the name of your preferred GP and their medical centre, please inform us and update the HTC when you move. We can ensure your GP is kept informed with summaries from each clinic or admission you have at the Alfred.

If specialist reports are required for various applications such as DSP, NDIS please ensure the writer details exactly what questions they are require answered. Such a request should be on the agency’s letterhead. Social Work is available to assist you in working out these processes.

These requests can be submitted to the individual team members including the Physiotherapists, Pain, Rheumatology and Psychology. Social Work similarly can provide advocacy and psycho-social support summaries as required.

Requests can be emailed through to haemophilia@alfred.org.au or by fax (03) 9076 3021

You can also seek information from:

The Royal Australian College of General Practitioners (RACGP), call 1800 472 247 or email racgp@racgp.org.au

Useful Link:

<https://www.betterhealth.vic.gov.au/health/servicesandsupport/seeing-a-doctor-or-general-practitioner>

WORLD HEMOPHILIA DAY

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel’s birthday.

This year the theme is Access for All. The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work

with developing countries with their GAP and Twinning Programs and Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

DID YOU KNOW

WFH estimates that over 75% of people living with hemophilia worldwide have not yet been identified and diagnosed.

Haemophilia Foundation Australia is a WFH member organisation and many Australian volunteers have been involved with WFH programs. HFA has supported many programs over the years and participated in the WFH Twinning Program and

various committees that work to achieve the objectives of WFH.

We are grateful that our community has access to high quality treatment but we recognise that many other parts of the world do not have access to diagnosis, treatment and care. Together as Australians, let’s take this opportunity to recog-

LIGHT IT UP RED

We have many locations and landmarks over Australia Lighting up Red in support of the day. These locations will be listed on HFA website. Keep an eye out and share photos on HFA social media platforms.



HFA will have some virtual activities available at <https://www.haemophilia.org.au/WHD>
For more information, virtual activities and Light It Up Red Landmarks visit <https://www.haemophilia.org.au/WHD>



**APRIL 17
2022**
**WORLD
HEMOPHILIA DAY**



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Partnering for impact in India: Bringing quality haemophilia care closer to home

Novo Nordisk Haemophilia Foundation

India is the world's second-most populous country and its seventh largest in terms of land mass. With a population of 1.38 billion, an estimated 138,000 people live with haemophilia in India, yet only around 15% have been diagnosed. This is due to a lack of diagnostic facilities and limited access to care, especially in rural areas.

That situation may soon be changing thanks to the latest project supported by the Novo Nordisk Haemophilia Foundation in India. Launched in 2020, the India 13 project aims to raise the quality of care across the country by strengthening seven centres to become national training and referral centres for bleeding disorders.

Shashank knows first-hand about the real impact of quality care. At 21 years of age, he lives in Bangalore where he is able to access care and pursue his education, but it wasn't always that way. His haemophilia A remained undiagnosed and untreated for years. Shashank's life changed when he began to receive quality care, not just for his physical symptoms but also for his mental health:

"Lack of access to medical care for my bleeds at a young age led to deformities in my knee, ankle and elbow. What was worse, realising that I was different from other kids led me to distance myself and avoid social contact. I was slowly falling into depression when I was introduced to the Haemophilia Society, Bangalore Chapter, and the Bangalore Medical College and Research Institute (BMRCI) centre. Thanks to the care of Dr Meera and the staff, including multiple counselling sessions, I was able to discover my potential, gain self-esteem and confidence in my abilities."

Dr Meera is a haematologist at the BMRCI centre in Bangalore, one of the seven national centres across the country participating in the NNHF-supported project carried out in partnership with the Ministry of Health, and the All India Institute of Medical Science (AIIMS) in New Delhi. The project started in early 2020, just before the COVID-19 pandemic began to wreak its devastating impact across India.

Dr Tulika Seth, head of haematology at AIIMS, has been instrumental in overseeing the project activities and coordinating among the different stakeholders. Dr Seth believes that teamwork has been the key to their success in challenging times:

"If I had to choose one word to describe this project, it would be partnership. In addition to equipping seven centres with the diagnostic and laboratory equipment needed to provide advanced diagnosis, we are training other centres so that they too are able to diagnose people with haemophilia. Training is provided remotely both by experts within the country and international experts from the UK and the US. So far, we've held virtual masterclasses for nurses, haematologists and physiotherapists; we plan to expand this to include lab technicians and dentists with in-person training sessions as soon as the COVID-19 situation allows."

All of this means that people with haemophilia in India, like Shashank, won't have to travel such great distances in future for diagnosis and care. This will help prevent the disability, mental health issues and premature deaths associated with bleeding disorders.

"This project is desperately needed because, despite the size of India, not many government hospitals are able to provide quality haemophilia care. Among those that do, the standard of care can vary widely due to disparities among facilities and skills. Standardising care at these centres is the first step in our strategy of developing referral hospitals in each state and bleeding disorder centres in every district," says Dr Seth.

Article first published 30 November 2021 on the NNHF Website at <https://nnhf.org/>

Sign up to volunteer for a project with NNHF at <https://nnhf.org/get-active/volunteer-for-a-project/>



Dr Tulika Seth, talking to a patient at the All India Institute of Medical Science, New Delhi, in 2019.

Despite the ongoing COVID-19 pandemic, Dr Tulika Seth and the project team have built strong training networks and obtained equipment to improve care for bleeding disorders at seven centres since the India 13 project began in 2020.



Shashank P. lives with haemophilia A with inhibitors in Bangalore, India.

REFLECTING ON THE MEN'S RETREAT

BY DAN KORN

After I'd been to one Men's Retreat I didn't need any convincing to come back again. I suspect this was true for many of the other guys who have been to one, and that may be down to the way it's a mini-holiday. You show up to a nice little rented farmhouse, meals are provided, there's some massage therapy available, and you can spend two days relaxing in country Victoria.

But in my case, I found a fellowship there I haven't been able to find anywhere else. There was a moment where a dozen of us were seated around a long table for dinner, someone asked to have a dish passed to him, and we all broke out laughing as it happened - because everyone around the table had a wonky elbow or knee, so no one could just reach out and hand it along. There was always a bit of adjustment first, an extra leaning over to make up for the distance that your arm couldn't straighten anymore.

Every now and then, at home, I'd catch myself making those awkward motions, but I had never seen it in anyone else. It's one thing to share stories about frustrating bleeds or stints in and out of hospital, but it's another to see that burden carried by everyone in the room, and carried without excuse or explanation. We haemophiliacs are sometimes an invisible in-group, but when you know what to look for, seeing it in every other bloke in the house that weekend is a powerful statement.

Looking back, I can't think of any other time when we haemos were a majority of the room, much less all of it. The sense of commonality in that moment, the literal community of it, turbo-charges the bonding. Since then I've been keeping up with the others throughout the year, not just at retreat time. Sometimes we text about footy, and other times - well, at least pre-COVID times - we'll plan a little gathering at

a pub if someone is coming from a regional town for a visit to the HTC.

I grew up in a different country, so those of you who are Victorian natives may already have a good sense of community through HFV events. But for me, having moved here less than ten years ago, going to the Men's Retreat has changed my perspective on where the core of my haemophilia is. I don't imagine it to be in the waiting room of the HTC anymore. It's once a year at Men's Retreat, and throughout the year at any of our other little unofficial meetups.

The next HFV Men's Retreat will take place 29 April 2022.

Thinking about attending your first Men's Retreat this year? Register your interest at: info@hfv.org.au

Past attendees, please let us know if your contact details have changed.



“After I'd been to one Men's Retreat I didn't need any convincing to come back again.”

Notices & Information

GETTING OLDER WITH A BLEEDING DISORDER

Would you like more information about living well as you get older?

HFA have put together a collection of resources for people with bleeding disorders.

Some topics covered are:

- Health & Wellbeing
- Work & Finances
- Accessing Services
- Recreation & Travel
- Planning for the Future
- Connecting to Others
- Support Networks

To access the "Getting Older with a Bleeding Disorder" information hub, visit:

<https://tinyurl.com/HFAgettingolder>

If you would like this information to be provided in another format, please contact HFV on:

03 9555 7595 or at info@hfv.org.au

WOMEN WITH BLEEDING DISORDERS

Women and girls with bleeding disorders often have a unique set of experiences and challenges, including underdiagnosis.

Visit HFA's information on Women with Bleeding Disorders to access resources on topics including:

- The Female Factors women and girls project
- von Willebrand's Disease in females
- Self-advocacy for women
- Haemophilia & carrying the haemophilia gene
- Personal stories

The website can be found at:

<https://tinyurl.com/WomenWithBleedingDisorders>

SUPPORT FOR CARERS

The Australian Government program Carer Gateway provides free services and support for carers including peer support, counselling, coaching and emergency respite.

To access Carer Gateway, call 1800 422 737 or visit carergateway.gov.au *Relay Service and Translations available.*

HFV provide additional support for carers in the form of Live Well Grants. To apply, please contact our office at: 03 9555 7375 or andrea@hfv.org.au

HAEMOPHILIA FOUNDATION
VICTORIA INC



13 Keith Street
Hampton East VIC 3188
Phone: 03 9555 7595
Mon - Thurs 8.30am - 4.30pm
* Due to the NBN we can no longer offer a fax service
info@hfv.org.au www.hfv.org.au

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EXECUTIVE MEMBER Donna Field

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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
Julia Ekert | Office Data & Product Manager
Nicola Hamilton | Physiotherapist
Wade Wright | Social Worker

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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:

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

Care and Counselling:

This is available through your treatment centre.

Magazine:

Your quarterly magazine offers information and details of upcoming events.

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 2021 ten members attended the retreat, including a number of first timers, all promising 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 2021 we will be offering a pottery class and lunch!

YOUTH GROUP

The Youth Group will be meeting up mid-year in 2021 to participate in a laser skirmish and bowling activity. We also have our actively involved Youth Leaders who are present at our family camp. They attend specific youth leadership training led by our formally trained youth leaders - an initiative developed by the leaders 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. In 2021 we will be offering a fun morning session mid-year that include circus skills, ninja warrior and minute to win it. This is an inclusive morning games session for kids with bleeding disorder, their sibling and their parents can join in too!

AUTUMN DIARY DATES

~~20 MARCH~~

HFV PICNIC (CANCELLED)

APRIL (DATE TBC)

VIRTUAL GAMES NIGHT

17 APRIL

WORLD HAEMOPHILIA DAY

29 APRIL - 1 MAY

HFV MEN'S RETREAT

13 MAY - 15 MAY

HFV COMMUNITY CAMP

REGISTER YOUR INTEREST AT INFO@HFV.ORG.AU TO
RECEIVE UPDATES FOR UPCOMING EVENTS

