

THE MISSING FACTOR

Connect, Support
& Empower -
through HFV social media

The power of
your story &
the real impact
of inhibitors



SPRING 2020

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Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

DIARY DATES

SEPTEMBER

26th - Community Online Adventure Trivia Night (See back page for details).

OCTOBER

11th - 17th Bleeding Disorders Awareness Week

NOVEMBER

19th - (Virtual) HFV Annual General Meeting

HFV is preparing for an **exciting and interesting Virtual AGM** this year, and the Notice of AGM will be EMAILED to you. Please ensure HFV have your current email address. If you've never attended an AGM due to distance, this AGM is for you and we hope you'll be able to join us!

DHHS Call to test service - COVID Testing Service

The Call-to-Test service will enable some of our most vulnerable to get tested for coronavirus (COVID-19) at home with a qualified health clinician. The service will provide access for people who cannot leave home due to injury, mobility or other eligible reasons.

Access to the Call-to-Test service will be available to individuals who have coronavirus (COVID-19) symptoms and meet the following criteria:

- people with an injury, chronic health issue, or frailty affecting mobility
- people with moderate to severe physical or psychosocial disability
- people with moderate to severe mental health or behavioural issues not otherwise classified as a psychosocial disability
- carers for a person with moderate to severe disability

www.dhhs.vic.gov.au/call-to-test-covid-19

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: Julia Broadbent



PRESIDENT'S REPORT

Hello everyone.

I am sure everyone will agree with me when I say this has been the strangest year of our times....and it is only August. As someone blessed to still have a job and able to work from home I am sitting at my makeshift desk (two building trestles and an old door from the garage) and watching the seasons change through a window to my street. When I first sat at this desk it was before the Easter bunny visit, end of summer and daylight savings coming to an end. Who would have thought I would still be sitting here? Autumn leaves have come and gone. The bareness of trees and cold, short dark days of winter are passing, and the blossom is now ready to burst into the beauty of Spring. And still I sit at my makeshift desk with no realistic idea of when things will change. A life where we all need to be indoors by 8:00pm seems like a B grade movie script and yet this is the life we now know in Melbourne and Mitchell Shire as part of Stage 4. With each passing week the challenges of living a life full of 'Groundhog' days become more and more.

In saying all this, rest assured HFV continue to get on with business as usual despite in a very different way. The committee and staff remain dedicated to the task at hand and to supporting you as our members. What a better way to continue with this work than to present yet another fabulous newsletter packed with interesting articles and information. Given our life of lockdown an excuse to take a break from streaming services and binge TV and enjoy a great read.

There is no doubt that new products and approaches to treatments continues to excite us all in the bleeding disorder community. This is certainly reflected in several articles in this edition. With more treatment options available as a community we will continue to be dependent on government processes and policy to fund medications and for those in authoritative positions to make decisions impacting

on our community and our diverse needs. We are currently experiencing challenges and working closely with the expertise of HFA to influence these critical decisions that impact for so many in our community.

Again, I am reminded of the need to be strong as a community. HFV plays a critical role in bringing us together as a community to connect and support each of you and to empower us to tell our story for advocacy when needed. My sincere thanks to those who have bravely shared their powerful story to benefit others. In this edition we include the transcript for their stories, and I encourage each of you to take time to read and appreciate the ongoing challenges that many continue to experience. I again want to thank the team at HFA so well led by Sharon for their undying commitment to the advocacy required to support us all across Australia. We are certainly blessed by those that look after us including the HTC's as well as our funders at DHHS.

Getting Older with bleeding disorders is becoming more and more complex as we better understand the needs of our ageing community members. HFA have released a critical brochure and information as a result of a high-quality research paper. The calibre of this work is second to none and has many important insights into the challenges ahead for us as a community. Please read the brochure included and explore further on the HFA website. There is little doubt that there will be many needs ahead for those of us ageing with a bleeding disorder and this piece of work gives such depth to advocacy, policy and the programs we will need to have in our future planning. Well done and yet again another example of the strength of our collective in sharing problems and tapping into limited resources effectively.

There are so many interesting articles to read as always in this edition. Bleeding Disorder Awareness week and an interesting article from Lifeblood for Blood Donor week. Again, we thank our Patron Prof Alison



Street who has generously shared some of her incredible body of work in sharing insights from the Asian Pacific Hemophilia Working group. World hep C day was commemorated in July and we take time to share the important messages and promotion across the globe by many. As we move into a world where hepatitis has less impact for our specific community, we always acknowledge those that still struggle with the aftermath left behind by hepatitis despite treatments. We also acknowledge the global impact that hepatitis continues to have on those not as privileged as us in Australia. Taking time to think of others globally that do not have access to products as we do is important for us all.

A shout out to our regional members. We would in other years be promoting and looking forward to our regional visits as an opportunity to connect with those in rural and remote areas. Ironically COVID has provided all of us the experience of living remotely from health providers and our extended families and supports...perhaps a tiny snapshot into what the challenges are for those that are often isolated at home due to illness and/or remoteness. A learning from this time will be a better understanding of isolation and an appreciation of our connection to each other and the things we can take for granted. We will be back out and about as soon as it is safe to do so. In the meantime, the team, both staff and committee is only a phone call or email away if you need support and we have a fabulous online community event booked for the 26th September so please join us for a great night in!

(continued on page 9)

The POWER of YOUR story

Recently, a few members generously assisted HFA with some advocacy work by sharing their stories in a short video. They have kindly shared their journeys here. Andrew and Naomi's stories are powerful and moving and cover the impact of inhibitors and of a new drug trial.

As the haemophilia treatment landscape evolves it may be worthwhile understanding what is involved in trials to keep as many options available to you. To be included in a clinical trial the investigators often require an accurate record of the number of bleeds and exposure days to treatment. A consideration in participant selection is for people living with haemophilia who are reliable and consistent in recording this information. The ABDR is a very efficient way of capturing this information and may help to keep your options open for new opportunities in the future.

It is difficult to fathom the journeys these families have endured, the challenges for their healthcare teams and the life changing impact one drug can have. We thank both Andrew and Naomi for sharing such personal accounts with us and are so very grateful to those researchers, behind the scenes, that make these huge advances in treatment possible and change the lives of many.

Hi, my name is Andrew and I am a person living with haemophilia A severe with inhibitors.

I'm from Melbourne Victoria and I am a senior project manager at the University of Melbourne.

I want to tell you about my story with haemophilia.

As a child I had 30% schooling attendance, all the way through to VCE. I spent a collective 8 years as an inpatient at the Royal Children's Hospital and The Alfred hospital here in Melbourne.

I have a long list of co-morbidities due to my haemophilia. I've had both my ankles fused, my knee replaced twice, I've lost 50% feeling in my left hand and I've got chronic arthritis.

From ages 5 - 20 I spent that time primarily in a wheelchair in hospital and on high dosage pain killers. I was on average bleeding one to two times per week. And having 2 to 3 doses of treatment to stop those bleeds every week. Out of those 52 bleeds I was having a year,

25% of those actually required hospitalisation and of those extended stays in hospital I was needing 10 -20 doses of treatment to stop the bleeding. When you add up the sheer numbers of that, it's 200 - 400 doses a year of treatment being used. I remember one year I had 180 doses to stop me from bleeding out from some lifesaving surgery that I had to have. My veins were so shot and the scars would raise suspicion on my arms that I was doing something different.

That all changed though in April 2016 and I get chills on the back of my neck when I talk about it. I got on a new drug called Hemlibra and since then I have had zero bleeds. I have had 1 hospitalisation in that time and that was for some orthopedic surgery so I could walk properly again.

I can't underestimate and you can't



understate how much this has changed my life. I have a wife, I now have a mortgage, I go to work, I am a functioning member of society, I pay my taxes and I live my life not in pain, not on pain killers and not having to have the unpredictability of not knowing what tomorrow is going to bring. I can now plan for 10, 20, 30 years into the future not wondering if I am going to have a bleed that will take my life. And most importantly in times like these I am taking up less resources in hospitals where every bed is so precious.

I can't understate how important this product is for people like me and our community as a whole.

Thank you.

My name is Naomi. My husband Matthew and I have 2 boys, Harrison 11 and Callum who is 8 and both have severe haemophilia A.

Both boys were diagnosed at birth as we have a family history of haemophilia. Both had ports put in when they were 13 months old to assist in the treatment 3 times a week of their haemophilia.

Life transitioned on and they both moved over to vein treatment pretty quickly. Harrison when he was 7 and Callum when he was about 3 or 4 and they had their ports removed on the same day in May 2016. At that stage Callum's inhibitors weren't causing us any issue, we knew that he had them but they weren't causing a problem. Ironically and unfortunately it was after he had his port out that he started to have bleeds for no reason whatsoever. He was pretty quickly changed over from treatments 3 times a week to treatments daily of Biostate. Unfortunately, his veins gave out and he had a port put back in and he was able to have treatments through that. Sometimes he would require more than one treatment a day to manage his bleeds.

He has had many, many hospital admissions over the time treating his bleeds, a lot were very painful bleeds, and he required a lot of long hospital stays. As a result he had missed a lot of school. He is between 6 - 12 months behind his peers in his school work.

For Prep, he pretty much missed the most of the year, last year and grade 2 he missed over a term of school. He struggles to make friends he's just missed out on so much...birthday parties, sports. He wasn't able to be involved in any of it.

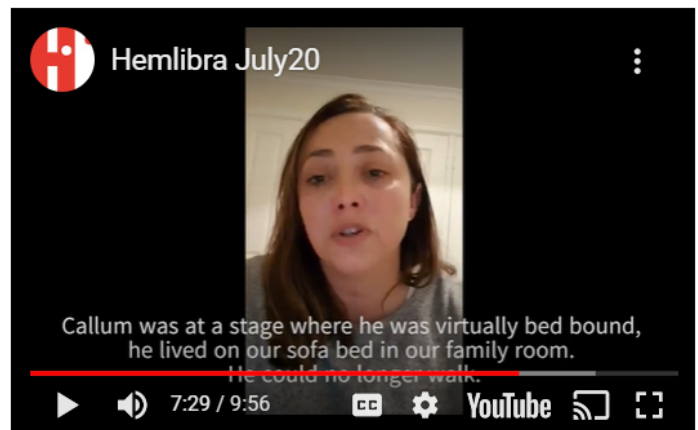
Over the time the treatments did work to tolerate his inhibitors but unfortunately he kept relapsing.

The third time he relapsed, last year in July 2019, essentially no treatments were working and he would have bleeds within an hour of being treated. So we were lucky to get compassionate access to Hemlibra.

Callum was at a stage where he was virtually bed bound, he lived on our sofa bed in our family room. He could no longer walk. When he tried to walk he would bleed into his hips, groins, calves, thigh muscles. He was having shoulder bleeds from trying to move himself around on the bed because his legs were in splints. It was a very difficult period for him.

It was very painful for him. In the space of a month last year he had 4 separate hospital admissions for very big painful bleeds. One admission he had for a lip bleed that just bled profusely and quite openly for 6 hours and he ended up in resus, tachycardic and about to pass out from the amount of blood he had lost. So from the 3rd time when he relapsed it seemed like nothing was going to work essentially, so we were very grateful to be given the chance to have access to Hemlibra. And it virtually just changed his life.

He's now able to walk, run, hop, skip, jump. He is back at school full time, he is back playing basketball and back on his one true love, his motorbike. And his haemophilia nurse really put it perfectly when she said she had never seen him so happy, she hadn't seen him so happy in years. And neither had we. He was just so happy to be able to be a little boy again.



It's been very stressful on a family. I often says it is stressful having haemophilia, having 2 boys with haemophilia is stressful enough but to add inhibitors on this just adds a whole other layer of stress and a whole other layer of unknown because you just don't know what's going to happen. You never knew if a bleed was going to happen that day, the next day, that night. You could never plan anything, it was just...sometimes a nightmare.

But we are eternally grateful for him to be on Hemlibra. It's made such a difference to us. We have a life, we have our lives back. We are able to go places and do things and we don't have to plan his treatments around that or cancel last minute because something has happened with him and we can't go.

We are eternally grateful he has his life back. He is back at school now trying to catch up with everyone but he is just loving being a boy and being like his mates and we are just so happy.

Thank you.



Did you know you can
watch WFH Virtual
Summit sessions
ON DEMAND



Please make the most of the sessions available to you through the WFH Virtual Summit. The On-Demand viewing will be available until June 2021. The sessions are by many world class health professionals that provide in-depth information and perspectives to educate us on managing bleeding disorders and what may be on the horizon for the future.

We have shared our overview of a session on gene therapy and managing expectations but for an accurate and comprehensive understanding we recommend watching this session on-demand.

To access On-Demand sessions go to www.wfh.org/virtual-summit/home and register... it is FREE!

Gene Therapy & Managing Expectations

...FROM A HAEMATOLOGIST'S PERSPECTIVE

A very interesting presentation was by Professor John Pasi who discussed the very relevant topic of managing expectations around gene therapy.

As you may be aware there has been some recent success in gene therapy for haemophilia and with that comes, hope, anticipation and optimism for our community. To avoid disappointment, there also needs to be a good understanding of the process for patients before they even start thinking about whether gene therapy will be an option for them. Not all patients will be able to access a gene therapy trial so it is important that the community is well aware of that.

Professor Pasi said "we need to be fully cognisant of the fact there are

many hurdles on the path to gene therapy."

"When we are talking to patients about gene therapy we need to manage that expectation in relation to eligibility. There are plenty of reasons why you might not be able to have that particular therapy. You may have seropositivity of antibodies to the AAV that is currently being used. You may have other illnesses that preclude you from the gene therapy. At the moment pretty much all the programs exclude people who have had a history of an inhibitor more or less at any time, not a current inhibitor but any inhibitor."

Professor Pasi discussed the great success of the gene therapy trials since 2017 and that they really exceeded all expectations in terms

of results. That has meant that the overall expectations of what can be achieved has moved significantly. There are huge advantages such as the one treatment but the drawback is that if you don't get the success you were hoping for you cannot be re-dosed which may impact your choices for the future. Basically, you need to be confident that you will be happy with the results.

But how can you predict the results? Professor Pasi explained that a good way to look at the results and manage your expectations is to not look at the mean or median (or average) results in gene therapy but to look at the minimum result and use that as a benchmark. If you are happy with the low end of the spectrum in terms of results

and potential impact on your life than that is a good starting point. Professor Pasi said “If we just talk about the expectation being the median then 50% people are not going to achieve that level and even if we think about the mean depending on how the graph is skewed a significant number of people are not going to meet that mean and if you don't meet it are you going to feel upset and are going to feel like you've lost out? What we really need to focus on now is a minimum realistic expectation, maybe not the middle and the average - that would be nice but what is it actually going to mean if you are one of the lower responders. What is that actually going to mean for you.”

There is a lot of focus on factor levels and specific numbers that can be reached with gene therapy. Professor Pasi noted that there needs to be less focus on the level number and more focus on potential impact to life. A small increase in factor level can have a huge impact on the quality of life for a patient so removing focus around achieving high factor levels will help to manage expectations and redirect to the more tangible impacts on improvement in life for these patients. Professor Pasi said “Patients shouldn't get too caught up on achieving high factor levels as relatively small level improvements can have life changing impacts. In relation to levels is this issue about how it pans out practically. Is it that actual level, is it a number, or is it the practicalities of what happens in life? Factor levels of 5-10%, 25% or 100%...in reality, if you are at any of those levels you are not going to need prophylaxis. You are going to have very low or zero bleeding and you are going to need next to no factor. And so, on a day to day basis somebody being treated with gene therapy to any one of those three levels would have a very similar pattern of life.” Professor Pasi also reminds us that although gene therapy may have



great results for many there will still be issues caused by long term haemophilia such as joint issues and those issues will still need to be managed.

Professor Pasi also discussed uncertainty. As with all trials uncertainty is still a factor and this is another consideration before embarking on a gene therapy trial. Inherent to trials is uncertainty which only time can reduce, so uncertainty remains a factor for significant consideration for potential trial patients.

For our community, we are really on the cusp of significant improvements in treatment and it is very important to consider our expectations, really understand what these treatments will mean for us in the future to help manage our expectations, advocate for ourselves and for our families.

Our HTC teams are highly knowledgeable on trials and emerging therapies and will always advocate for the best possible treatment for you however having an understanding of limitations and options available to you may help mitigate disappointment eg around eligibility and appropriateness. You can always discuss your current treatment and what future options may be realistic considerations with your HTC team.

Gene therapy may not be an option for you, that may change in the

future but there are other emerging therapies that may well be suited to you in the future. It is an exciting time for our community and the future is bright.

Again, please make the most of the sessions available to you through the WFH Virtual Summit.

The On-Demand viewing will be available until June 2021. The sessions are by many world class health professionals that provide in-depth information and perspectives to educate us on managing bleeding disorders and what may be on the horizon for the future.

Julia Broadbent

John Pasi is Professor of Haemostasis and Thrombosis at The Royal London Hospital, Barts and the London School of Medicine and Dentistry and Haemophilia Centre Director.

To watch sessions from the WFH Virtual Summit go to their website and register for free:

www.wfh.org/virtual-summit/home

Aspirations for better haemophilia care in the Asia-Pacific Region

As I scrolled through the WFH Virtual Summit posters available online I came across one by Dr Alison Street, our HFV Patron. Dr Street is currently grounded, as we all are, but under normal circumstances is often travelling around the globe continuing her work and commitment to the bleeding disorders community. As I read through Dr Street's poster I not only felt privileged that we have such an incredible advocate as our HFV Patron but also that many other people in the wider bleeding disorders community, from many different countries, backgrounds and challenges also benefit from Alison's tremendous knowledge, leadership and compassion. Below is the information included in the poster highlighting Alison's work with the Asia Pacific Hemophilia Working Group, which also serves as a reminder of how fortunate we are in Australia to have such comprehensive care. (Dr Huyen Tran, Director of the Alfred HTC, is also a member of the steering committee of 16 doctors across the Asia Pacific region).

INTRODUCTION

The Asia Pacific (AP) region has more than 60% of the world's population. The WFH Annual Global Survey shows that large number of persons with haemophilia remain to be diagnosed in this region.

The emerging economies of this region have many needs and strong aspirations for better haemophilia care.

To address these needs, the Asia Pacific Hemophilia Working Group (APHWG) was formed in 2014 as an independent group of health professionals (HPs) from the region.

The countries currently represented include Australia, China, Hong Kong, India, Japan, Malaysia, Singapore, South Korea, Taiwan, Thailand and Vietnam.

APHWG is governed by a steering committee of health care professionals who are experts in the field of haemophilia and allied disorders and with diverse regional membership.



There are three working groups -

- Education and Training
- Publications and Scientific
- Registry

APHWG collaborates with WFH through a formal Agreement of Collaboration. An annual scientific meeting is planned from 2021.

1. Education and Training:

Understanding that continued education for all medical professionals involved in haemophilia care in Asia-Pacific remains the cornerstone for improving standards of care for PWH. Since 2017 the APHWG has been organizing training workshops for physicians, nurses, musculoskeletal specialists and hemostasis laboratory specialists from across the Asia Pacific countries. The trainings were held in Cambodia, India, Myanmar and Thai-

land. The workshops have covered basic and advanced hematology laboratory diagnosis of bleeding disorders, musculo-skeletal assessment and management and the scope of comprehensive care.

2. Publications:

The APHWG has published a survey of characteristics and current needs of HTCs in the region. It has also published the Principle of Haemophilia Care-Asia Pacific; its vision of principles for advancing regional hemophilia care endorsing on a similar overall framework outlined by the EAHAD (European Association for Haemophilia and Allied Disorders).

3. Asia Pacific Bleeding Disorder Registry (APBDR):

Documentation of demography, diagnosis and outcomes data is critical for good management of people with bleeding disorders and promotes the culture of outcome data collection using standardised formats by health care professional. APHWG has developed and implemented APBDR, which

is a web-based data system based on the foundations established by WFH. APHWG therefore encourages HTC to house relevant bleeding disorders-related patient data.

There is a wide network of haemophilia treatment centers around the Asia Pacific countries with expertise in different aspects of haemophilia care. APHWG has compiled and updated a directory of the HTCs across the countries which will be a valuable source of information for the PWHs, caregivers and health professionals involved in its care.

We are developing our strategies to include regional intelligence on appropriate platforms available to participants. We also have previously published feedback on regional training needs "A survey of characteristics and current educational needs of hemophilia treatment centers within Asia Pacific" (Joyce C.M.,2018) and are undertaking immediate and twelve month review of 2019 workshops to refine content for relevance and innovation.

We are grateful for unrestricted funding support from Baxalta, now part of Shire, who has funded the educational activities of APHWG. And also Diagnostica Stago who has fully sponsored the basic laboratory workshops.

Our organisation is soon to be renamed as Association for Haemophilia and Allied Disorder-Asia Pacific (AHAD-AP).

MISSION AND OBJECTIVES

APHWG exists to improve care for people at risk for haemophilia and other hereditary bleeding disorders in the Asia Pacific Region.

The objectives are:

1. Addressing training and educational needs of regional HCPs through relevant programs
2. Developing and publishing scientific documents necessary for improving regional hemophilia care.
3. Promoting culture of outcomes data collection at hemophilia treatment centres (HTC) to optimize care with the long term goal of establishing national and regional registries.
4. Establishing regional collaborative groups for relevant research.

CONCLUSION

APHWG activities are impacting hemophilia care in this region. The disruption of COVID encourages us to explore different platforms to deliver our programs. These will continue in collaboration with WFH and be reviewed frequently for quality, relevance and participant satisfaction.

RESOURCES

APHWG Website: www.aphwg.org/

Continued from page 3...

Thanks to the HTC crew at the Alfred. Always enjoy reading the Q&A contribution as an insight to the working of the team and how well you consider the needs of our community.

Mindfulness is something many of us may have heard about and may have dabbled in at times. Now more than ever is a time to consider how you may build some time into your day to bring the positivity of mindfulness into our lives. It takes practice but well worth the effort. Tiny habits article will give you suggestions for ways to embrace strategies to approach the ongoing stages of lock-down that we are experiencing.

I am reminded in these times of the resilience we all share as a community. Being in Stage 4 lock-down has limited our outside activities and our connection to the outside world. It has also provided an insight into the life many who have grown up with bleeding disorders have endured for their earlier years. Those of us benefiting from prophylaxis and amazing healthcare have never had to experience lengthy hospital stays or times locked down with mobility issues. COVID has given us all a tiny insight into how challenging it is to entertain ourselves for weeks on end when locked away from our lifestyle. Let's hope we will move into a freer existence in coming months although there continues to be so many unknowns. However I intend to keep the learnings from the past months with me and moving forward intend to not take so much for granted my time with family, my freedoms to come and go as I wish and my feeling of connection to the community – both physically and the haemophilia community.

Look after yourselves and each other and look forward to a time when we can again meet face to face in our peer support programs. In the meantime, the team at HFV continue to do our best to connect, support and empower under unprecedented times. Never hesitate to reach out. We are here for you even if it is virtually. Stay well, stay safe and stay connected.

Leonie Demos
HFV President



ASK US

Q AND A'S WITH ALEX & JANE - ALFRED HOSPITAL HTC TEAM

Living & Working in a time of COVID-19



Q. I have my annual review with the HTC coming up soon so what's happening now?

At the HTC since COVID-19 began having an impact on Victorians, the HTC has moved to using the telehealth system as much as possible to minimise the risk of exposure and to respond to the needs of our patient group and their families. However, if the medical scenario warrants a face-to-face clinical assessment, one will be requested. Please be assured we are taking all necessary precautions in face to face encounters with social distancing, minimising the amount of people present, hand sanitizer is available. Wearing of a face mask is now mandatory once outside of your home, so please do not take any unnecessary risks when commuting between home and the Alfred HTC. If you don't have the technology for telehealth we can telephone you. Please ensure the HTC has your correct contact details at all times.

Are you feeling unwell on the day of a face to face contact with the HTC? If you were coming in and have any cold/flu symptoms and/or you are waiting for COVID testing results, please do not come, call ahead and we can reschedule a non-urgent appointment. Get tested first at your GP or nearest testing site then self-isolate at home until you get your result please.

In an emergency situation and you are heading to the Alfred Emergency Department (ED) (or any hospital ED for that matter) you MUST tell ED about any cold type symptoms in addition to the bleed or injury. Due to the changing impact of COVID-19 we do not allow visitors and you should come alone (unless a carer is medically needed).

Q. What if I get stopped by the police or defence services doing spot checks on my way to the Alfred ED or the HTC for my face to face appointment?

We would suggest producing your ABDR card that confirms you are an Alfred patient and advise you are on the way to the ED to be seen due to your bleed. If you have telephoned the HTC in business hours and one of the HTC nurses or a doctor has requested you attend, please keep record of who you have spoken with. Your enquirer may want to verify with whoever you have spoken with.

If you have seen your GP and they have advised you to go to ED, please ask for a covering letter to the Alfred ED and produce this if stopped.

Q. I'm not sure if I should or want to go to work at the moment. Can I work from home? Do I need a medical letter as well?

Before we start, is your employer aware of your bleeding disorder?

Do you have any concerns about disclosure of this in the work place? Is your Superannuation Company aware of your pre-existing condition?

Having a bleeding disorder does not pose any exceptional risk of COVID-19 transmission!

If your job allows for working from home as many of us have commenced doing, (please seek your employers support first) you should be provided with the means to continue to carry out your employment at home as though you were in the work place. This means remote access to your work systems and records, providing the IT support and correct equipment in order to do so. Some employers are providing a small reimbursement for the additional cost of working from home such as internet access costs. Again query this with your employer.

For any of you with a compromised immune system or respiratory conditions, adhering to the rules of COVID-19 isolation is essential to your health care. We are especially happy to provide a letter supporting your request to work from home. If you are working in a non-essential industry or field, you may have been ordered to cease work. Please enquire what your entitlements are with your employer i.e. Annual leave.

Understand the symptoms

Has your employer enquired about JobKeeper? Have you applied for JobSeeker?

MINIMISING THE RISKS

It's also cold and flu season, have you had your flu injection or discussed it with the HTC.

1. Hand washing for 20 seconds with warm water and soap,
2. Using hand sanitizer responsibly (do you have any skin irritations?)
3. Minimising face touching
4. Face mask wearing – now mandatory!
5. Got a cough – remember to cough into the crease of your elbow NOT your hand and away from others around you
6. I personally am additionally mindful of touching surfaces in public such as a door knob, a press button, you can use some disposable barrier such as a tissue, some people wear disposable gloves or I use my pick up reacher stick! Especially handy in not having to bend over as we get older and greyer!











DO YOU HAVE ANY SYMPTOMS? CALL THE CORONA VIRUS



HOTLINE

As a reminder, if you are unwell in any way, you are advised to not attend the work place and should self-isolate for 14 days if you are awaiting test results.

What are the symptoms of coronavirus (COVID-19)?

	COVID-19	Colds	Flu
 Aches and pain	Sometimes	Rare	Common
 Cough	Common (usually dry)	Common	Common (usually dry)
 Diarrhoea	Rare	No	Sometimes (children)
 Fatigue	Sometimes	Sometimes	Common
 Fever	Common	Rare	Common
 Headache	Sometimes	Common	Common
 Runny or stuffy nose	Sometimes	Common	Sometimes
 Shortness of breath	Sometimes	No	No
 Sneezing	No	Common	No
 Sore throat	Sometimes	Common	Common

healthdirect

If you have any of the symptoms, however mild, you should seek advice and get tested. To get further advice, call the 24-hour coronavirus hotline 1800 675 398, your general practitioner or use our on-line self-assessment tool. <https://www.dhhs.vic.gov.au/coronavirus-self-assessment>

The symptoms to watch out for are:

- Loss or changes in sense of smell or taste
- Fever
- Chills or sweats
- Cough
- Sore throat
- Shortness of breath
- Runny nose

In certain circumstances headache, muscle soreness, stuffy nose, nausea, vomiting and diarrhoea may also be considered.

(source: <https://www.dhhs.vic.gov.au/victorian-public-coronavirus-disease-covid-19>)

Useful links:-

<https://www.dhhs.vic.gov.au/victorian-public-coronavirus-disease-covid-19>
<https://www.healthdirect.gov.au/>
<https://www.pm.gov.au/media/jobkeeper-payment-and-income-support-extended>
<https://www.servicesaustralia.gov.au/individuals/news/how-coronavirus-supplement-and-eligibility-some-income-support-payments-are-changing>

Alex Coombs & Jane Portnoy
Social Workers, Haemophilia & Other Inherited Disorders Team
 Alfred Health

TINY HABITS

As I write this, Australia is slowly lifting the restrictions that were put in place to keep us safe around the COVID 19 pandemic, with new guidelines about the numbers of people who can be in cafes, shops, etc. I wonder if this is an opportunity for each of us to think about a possible 'new normal' in our own lives. Has the pandemic brought about changes in your own lives that you would like to continue into the future, new routines, new experiences or a return to activities our parents or grandparents were involved in? For some, they have been able to invest time in gardening – growing their own food, sewing and making their own clothes, baking bread and other items that they would normally run down to the shops to buy. Perhaps it has given you time to think about what you prioritise in your days and weeks or what you have missed – meals out with friends and extended family, seeing grandchildren, nieces or nephews or just spending time with people who don't live in the same household as you. Maybe you have valued your time on your own and with your family, away from the hustle and bustle of shopping centres (or is that just me?).

On the other hand, maybe the restrictions have led to increased snacking, decreased exercise, poor sleep, increased alcohol consumption – things that you may not want to take into the 'new normal'. The timing might just be right, if you want to take this opportunity to look at what you value, to make small changes which could make a big difference in your life.

A suggestion is to start small and to start with one change first. Make it a routine and look for changes that are helpful for you. I am currently finishing a Certificate in Creating Positive Change and have been introduced to the work of BJ Fogg who writes about tiny habits. From his research he recommends 3 simple steps to creating changes you want in your life.

1. Make it tiny – consider the changes you want to make and scale it down to something really small. So, BJ Fogg wanted to improve his fitness. He now can do 50, 60, 70 + push ups a day, but he didn't start there. He scaled it back to 2 push ups.

2. Find an anchor - link your tiny habit to a specific routine you already do in your life, to trigger a reminder. It helps to use statements such as 'After I _____, I will _____'. So, for BJ Fogg he cemented his habit 'After I go to the bathroom, I will do 2 push ups'.

3. Celebrate your successes – this is linked to understanding that emotions create habits. If, when you do something, you have a strong positive emotion immediately, the next time you won't have to decide, your brain will lead you to seeking that strong positive emotion and you will do it automatically. BJ Fogg says "awesome" out loud once he has done his push ups. You might do a celebration dance, or something similar, it just needs to be immediate. Even tiny successes can loom large in your minds, so when you feel successful, you keep doing stuff. Once you have this cemented, you can then increase the tiny step.

Using BJ Fogg's example, he started with 2 push ups, but then increased to 5, then 10. In his TED talk, he says he now might do more than his planned number for 'extra credit'. Celebrating your success is very important in these steps. Put simply, BJ Fogg says emotions create habits. If you have to decide and deliberate whether to do your activity, like doing push ups, going for a walk, eating healthier food it isn't a habit. But if you celebrate this success, like celebrating 2 push ups, you are really celebrating that you are changing your behaviour and learning how to change. Another suggestion he has is "After my feet touch the floor in the morning, I will say, 'It's going to be a great day'". He also reports that if it isn't working for you, consider scaling it back even more. So, if your tiny habit is to walk 15 minutes a day and you aren't finding this is happening, your first tiny habit may simply be, for example, 'when I get up in the morning, I will put on my walking shoes'. Celebrate that success, 'well done!'. Once this has become a habit/routine, you can then add your next tiny habit to 'when I put on my walking shoes I will walk for 5 minutes' and celebrate that habit. To learn more, check out BJ Fogg's TEDx Talk 'Forget big change, start with a tiny habit' Ref: "Making positive psychology work #67 – BJ Fogg Cheat Sheet. www.michellemcquaid.com

Loretta Riley
Advanced Social Worker,
Royal Brisbane and Women's
Hospital HTC Team.

Featured in HFQ's Winter 2020
edition of The H Factor.



As HFV develop more ways to connect, support and empower our community we have entered the world of social media and are currently actively using Facebook and Instagram. As we use these platforms to enhance the capabilities of HFV, we need to remind ourselves of the risks that can be involved. The eSafety Commissioner website has a huge range of valuable resources that can help keep you mindful of some of the risks posed to you and your family from online activity.

Understand the risks of being online and what you can do to have a safer experience - information from the e-Safety Commissioner

Social media services and online chat are great ways to stay in touch and find new friends, but there are also risks.

The landscape of social media is evolving. Traditional social media services like Facebook, Instagram and Twitter are great ways to stay in touch and keep across the latest news and trends. Private messaging apps like WhatsApp, Facebook Messenger and Snapchat are also increasingly popular. Google Docs is even being used as a chat app by young people.

What are the risks?

- **Anonymity** — it can be easier to say and do things online that you might not do offline, which can lead to damaging or negative experiences for others.
- **Cyberbullying and online abuse** — online abuse and harassment are a risk for anyone using social media and chat apps.
- **Image-based abuse** — an intimate image of you could be shared online without your consent.
- **Sharing too much information** — for example, photos from a party might be OK for close friends to see but can become an issue if shared more widely and could damage your digital reputation.
- **Not protecting your personal information** — account details and location-based information can be used inappropriately by others to find you or access your online accounts.

It is important that you understand the risks associated with disclosing information about yourself online and know how to manage both your privacy and online friends.

• **Treating online friends as real friends** — it's easy for people to lie online, including those who are seeking children and young people in order to abuse them. Make sure you are careful about how well you really know your online 'friends'.

What are location-based services?

Many social media and chat apps take advantage of location-based services, which enable users to report their physical location to others via their mobile phone. By using this function, users can physically locate friends and others and see where they are. You can also 'check-in' from a location to let others know your whereabouts.

On some social media services, the location-based functions are turned on by default. To manage these services, and retain your privacy, review your privacy settings to block the function or to limit who sees your location-based information.

What can I do to have a safer experience while using social media and online chat?

Limit your friend list — don't 'friend' random people or allow people you don't know to 'follow' your social media accounts.

Adjust your privacy settings — make your accounts private so that only friends you know face-to-face can see what you post.

Your personal information is valuable — don't share it. Learn more about how to protect your personal information.

Protect your digital reputation — think before you share something and ask yourself, would you want anyone to see this in five years' time? Once you share something you lose control of it — remember that once a message, photo or video has been shared online, you may not be able to control where it goes or how long it stays online.

Be careful who you trust — not everyone online is who they say they are. Look out for things that don't add up — such as another user whose online profile is not consistent with what you see and hear when you talk or chat with them.

If someone says 'my web cam is broken', this may indicate that they are trying to scam or deceive you.

How do I control my privacy settings?

All social media sites have their own version of 'default' privacy and security settings. It is important that you know how the app or service works and how to change the settings to protect your personal information. It is also a good idea to check your privacy settings regularly, as sometimes updates to social media services or apps may also change the 'default' privacy settings.

The eSafety Guide gives you access to step-by-step instructions about how to control your privacy settings for many social media services, apps

and games.

What to do if things go wrong?

If someone is threatening or harassing you online, read our tips and advice about how to deal with cyberbullying (for people under the age of 18) or how to deal with adult cyber abuse. You can also report cyberbullying to us.

If you are experiencing online abuse or stalking from a current or former partner, read our advice on how to deal with technology-facilitated abuse as part of domestic and family violence.

If someone has shared, or is threatening to share, an intimate, nude or sexual image of you, you can make an image-based abuse report to us. Find out more about image-based abuse.

If someone is contacting you and you don't want them to, read our advice about unwanted contact, information about the risks of social media and chat apps by reading about the big issues and exploring our skills and advice articles.

Teachers and educators can use classroom resources about social media and online safety, including Cybersmart Challenge, Tagged and GameOn.

Please go to www.esafety.gov.au to review the extensive resources available.

www.esafety.gov.au

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Proud to be part of National Blood Donor Week



HFV were delighted to represent HFA at the recent National Blood Donors Week online morning tea.

We joined forces with the Thalassaemia & Sickle Cell Australia (TASCA) and Australian Red Cross Lifeblood teams to highlight the importance of blood donation within our communities.

Shauna from the HFACT discussed how vital donations were to her ongoing treatment for von Willebrand Disease. Without those donations she would not be able to live the life she has. Shauna requires a high number of donations for her treatment and she expressed tremendous gratitude to those donors who really do provide Shauna with the gift of life.

Robbin, a member of TASCA, talked about his daughter's condition and the regular treatments she requires from donations, highlighting the constant need of donors to help manage conditions such as thalassaemia.

Elle from Lifeblood shared a fascinating presentation explaining what donations are used for and what supply is required throughout Australia. There is lots of valuable information on their website. If you'd like to learn more please go to www.lifeblood.org.au.

Can I donate if I have a bleeding disorder?

Maybe. Eligibility for different types of bleeding and blood disorders varies and may be based on your individual circumstances.

Please call Lifeblood on 13 14 95 to learn if you can donate.

GRATITUDE is an interesting concept

Gratitude is an interesting concept. Medical experts around the world advocate practising it to improve our mental and physical health, reduce stress and enhance relationships.

At the beginning of 2020, I would have been hard pressed to imagine I could be more grateful to Australia's half a million life giving blood donors. But it turns out that gratitude, much like love, doesn't have a finite limit and the well does not run dry.

As we approach(ed) World Blood Donor Day on June 14, a day designed to remind us all that safe blood and blood products are indeed the lifeblood of an effective health system, I can't help but reflect on the year that has been.

2020 has presented unprecedented challenges for us all, but our donors have displayed bravery, selflessness, compassion, patience, adaptability and a sense of community to ensure all Australians have continued to receive the blood products they need through this pandemic.

We've asked a lot from our donors this year. In March we asked for 14,000 Australians to roll up their sleeves in the lead-up to Easter to help prevent a potential blood shortage, as coronavirus restrictions took hold across the country. Despite the fact none of us knew what impact COVID-19 was going to have on Australia or the exact threat it posed, thousands of people braved the uncertainty to leave their homes for the essential service of blood and plasma donation. In fact, we saw our biggest response to a call out ever with collection records



broken around the country.

As a result, we found ourselves in the unusual position of having to reschedule some donations and asking people to be patient as they tried to find available appointments. Thank you to our donors for their patience and understanding.

Things were changing in our Lifeblood Donor Centres too. Social distancing, ramping up of our already stringent cleaning regimes, and the introduction of added wellness checks meant wait times were sometimes longer. Our donors responded with good grace and humour.

Coronavirus has not stopped the need for blood and plasma. People have continued to be involved in road accidents, needing large volumes of blood for transfusions. Cancer patients have still needed support to survive their treatment, and women have continued to experience complications while giving birth. These are just some of the Australians who rely on the 29,000 donations needed every week across the nation.

As we move through this pandemic, I'd like to say a special thank you to the hundreds of donors who've

recovered from COVID-19 and donated their plasma which contains precious anti bodies. This plasma will be used to treat patients in clinical trials, both as a form of direct treatment and as a medication called COVID-19 Immunoglobulin. We're so proud to be able to support such important work through clinical trials, but couldn't do it without our donors.

At Lifeblood, National Blood Donor Week and World Blood Donor Day are usually celebrated with thank you events around the country. But, just like the millions of Australians who have celebrated birthdays, anniversaries and other special occasions a little differently this year, we will be too. Although we can't celebrate together, it doesn't diminish the gratitude we feel towards each and every blood donor for giving life to our most vulnerable Australian patients.

I know the saying is 'thanks a million' but I'd like to up the stakes and say 'thanks 1.5 million' to reflect the number of donations we received last year from 500,000 donors. I want to publicly thank them for their commitment to the health of the nation. Thank you for continuing to donate in the face of upheaval, for rolling up your sleeves even as you face uncertainty, and for keeping Australia's lifeblood flowing.

**Shelly Park, Chief Executive,
Australian Red Cross Lifeblood**

www.lifeblood.com.au



Stem cell project aims to better understand impact of COVID-19 on different organs



Researchers at the Murdoch Children's Research Institute (MCRI), with other Melbourne-based partners, will use human stem cells to better understand the effects of COVID-19 on different organs after being awarded a State Government grant.

Medical Research Minister Jaala Pulford today (30th July) announced the stem cell initiative was among the projects to share in \$5.5 million from the government's COVID-19 Research Fund.

The MCRI project has also received an additional \$600,000 in philanthropic support from the Stafford Fox Medical Research Foundation (SFMRF).

MCRI Theme Director of Cell Biology Professor Melissa Little said the project team would use human-derived stem cells to better understand the virus's effects on different organ systems in the body including the lungs, heart, kidneys, brain, immune system and blood vessels, to support the development of targeted treatments.

The collaborative study which includes The Peter Doherty Institute for Infection and Immunity, The Australian Regenerative Medicine Institute (ARMI), and the Walter and Eliza Hall Institute of Medical Research, will benefit from cutting edge stem cell processing equipment, which will recreate human tissues affected in COVID-19 patients.

The Stafford Fox Medical Research Foundation Stem Cell Based Disease Modelling Facility at MCRI also provides capacity to perform rapid drug screening to allow for swift transition from diagnosis to treatment.

Professor Little said the research team's ability to combine different cell types would allow them to investigate how the virus spreads in organs and how infected cells respond to each other.

"There is growing evidence that SARS-CoV-2 can damage organs beyond lungs, including the heart, blood vessels, immune cells, kidney and even neural tissue. But a limited understanding of the impact of SARS-CoV-2 on such tissues limits our capacity to treat patients in the most appropriate way and anticipate long-term complications," she said.

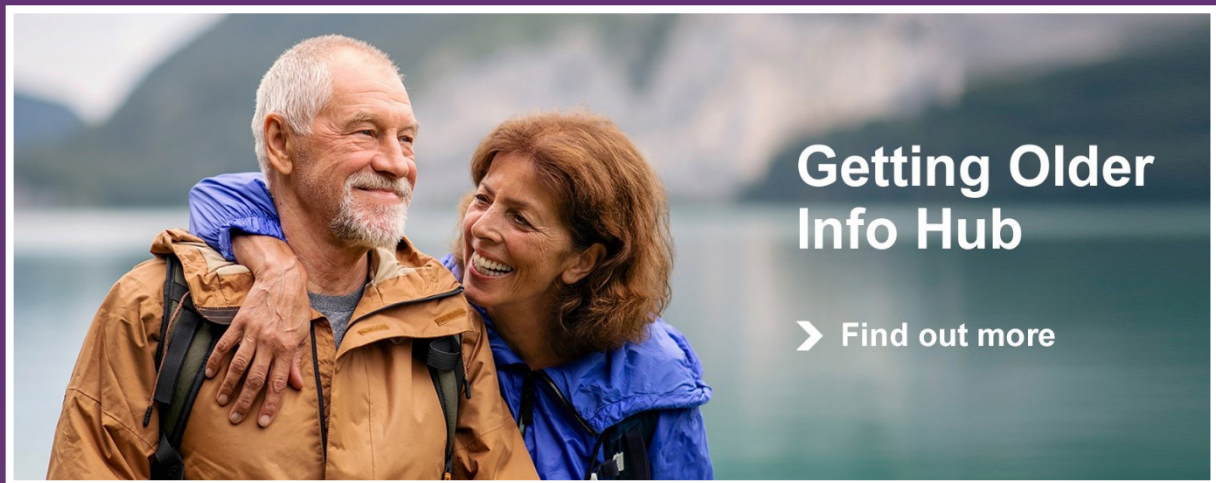
"This collaborative program will increase our understanding of disease pathology, identify underlying risk factors, change clinical care to protect the patient from severe complications, facilitate the development of targeted treatment options and better prepare us for the next pandemic."

About MCRI

The Murdoch Children's Research Institute (MCRI) is the largest child health research institute in Australia committed to making discoveries and developing treatments to improve child and adolescent health in Australia and around the world. They are pioneering new treatments, trialling better vaccines and improving ways of diagnosing and helping sick babies, children and adolescents. It is one of the only research institutes in Australia to offer genetic testing to find answers for families of children with previously undiagnosed conditions.

Reprinted with permission from MCRI

HFA GETTING OLDER REPORT UPDATE FROM THE HFA TEAM



The HFA Getting Older with a bleeding disorder needs assessment report was published in May 2020.

The report describes the needs of older people with bleeding disorders and the needs of their partners, family and carers. It includes proposed solutions and recommendations for an HFA national strategy.

Many members of the community, health professionals and other experts contributed to the needs assessment through interviews, community forums, the HFA Getting Older Community Survey and the PROBE Australia Study. Our thanks to all involved for their valuable input.

There are two versions:

- The full report - with all the details of findings and recommendations
- A community report – a short summary of the findings and suggested solutions

These are available online on the HFA website www.haemophilia.org.au and in print. A copy of the community report is included with this issue of The Missing Factor. If you would like a print copy of the full report, contact HFA on hfaust@haemophilia.org.au or phone 1800 807 173.

And check out the new Getting Older Info Hub on the HFA website -
www.haemophilia.org.au/getting-older

Your go-to zone to find online information on getting older with a bleeding disorder!



WORLD HEPATITIS DAY 2020

We mark World Hepatitis Day globally on 28 July. In 2020 we asked our community to help with the worldwide goal of hepatitis elimination by 2030 by starting a conversation - talking to friends, family or a doctor.

New revolutionary hepatitis C treatments are widely available in Australia. They have very high cure rates. Treatment is simple - tablets not injections, few if any side effects.

WHAT ARE THE ISSUES FOR THE BLEEDING DISORDERS COMMUNITY?

Many Australians with bleeding disorders and hep C have now had treatment and been cured. See their stories on the World Hepatitis Day page on the HFA website - <https://tinyurl.com/BD-WHepD2020>.

Have you been cured of hep C? How is your liver going? Ask your hepatitis specialist or GP if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need ongoing care of your liver.

Some people with bleeding disorders or who carry the gene may not realise they have hep C. You could be at risk if you ever had a blood product before 1993. Is this you or someone you know? Have you ever been tested for hep C? If not, now is the time to talk to your doctor about a hepatitis test - and have treatment to be cured, if you do have hep C!

Thousands of Australians are now living free of hep C, but many have not yet had treatment. Treatment is simple and nearly all are cured – start the conversation.

There is a small number of people with bleeding disorders and hep C whose treatment has not yet been successful. Close liaison between their hepatitis specialists and their Haemophilia Treatment Centre is very important for their care. Research into new and improved hep C treatments continues.

FOR MORE INFORMATION VISIT

- www.world.hepatitisday.org.au
- The HFA World Hepatitis Day page - <https://tinyurl.com/BD-WHepD2020>

**WORLD HEPATITIS DAY
28 JULY**

**Let's
Talk
Hep**

Hepatitis B and C are viruses that can damage your liver and lead to liver cancer...

You've been cured of hep C! How is your liver going?

Ask your doctor if you still need regular liver checks.

hepatitis australia

worldhepatitisday.org.au/quiz
#LetsTalkHep | 1800 437 222

H+

Images used are stock photos and the associated messaging may not represent the personal situation, views or beliefs of the people in the images.

Bleeding Disorders Awareness Week 2020

Bleeding Disorders Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia during the week of **11-17 October 2020**.

BDAW will be looking at quite different for us this year with the likely COVID-19 restrictions still in place.

We are hoping that we may be able to get together with limited numbers of people, such as a family or close friends to celebrate BDAW in our usual ways however it is more likely that we will have to take our events online....luckily many of us are now skilled in using online platforms so we can still power ahead in slightly different ways! We can still have an exciting campaign that can include many fun things that all ages can get involved in!



The theme of the week is **One Community, Many Faces!**

We will showcase our community and highlight the many different bleeding disorders and experiences.

GO RED FOR BLEEDING DISORDERS

Looking for something to do during Bleeding Disorders Awareness Week either face to face or virtual?

Host a red-themed event and Go Red For Bleeding Disorders! Some quick ideas are:

- Host a red-themed virtual morning tea
 - Host an online Red Cake Day
 - Dress red for a cocktail night
- Host a red themed 'crafternoon'
- Wear red in support of the day

More information and ideas will be on www.haemophilia.org.au/BDAW
HFA will not be able to provide any promotional packs this year due to COVID-19 restrictions but we will have it all downloadable online. For downloads and information visit www.haemophilia.org.au or contact HFA 03 9885 7800 or contact us at info@hfv.org.au

LIVE WELL FUNDING

HAEMOPHILIA FOUNDATION VICTORIA



HFV have small amounts of funding available to assist those that need help with costs associated with their bleeding disorder.

Not too sure if you can apply? Here is the following three criteria mostly used by committee to determine suitability of applications:

1. Will it improve a possible health outcome?
2. Are there any other resources available or other funding to the applicant?
3. Will it improve the applicant's quality of life?



The application process is very simple and straightforward and committee really encourage members to consider Live Well program as an option. Items approved in past 12 months include educational resources, medications, home ramps, personal health care, child swimming lessons.



Still unsure? You can send andrea@hfv.org.au a confidential email first. All applications are confidential and de-identified prior to review by the committee.

Go to www.hfv.org.au/support-services/services



ACTION CALENDAR - FOR FAMILIES



30 actions to help parents look after themselves and their families in challenging times. Please use and share

- | | | | | | | |
|---|--|---|---|--|---|---|
| 1 Go on a smile collecting mission, starting with a smile in the mirror | 2 Choose one song each and arrange a family dance off | 3 Send someone a message to show you really appreciate them | 4 Take turns to notice 3 things around you that are beautiful | 5 Be kind to yourself and others | 6 Together, make a list of things you are grateful for | 7 Think of a goal to work towards and do one thing to get started |
| 8 Take a mindful walk together and notice what you see hear and smell | 9 Play Musical Statues | 10 Create a bedtime routine together to help with sleep | 11 Bake cupcakes and decorate them as gifts for each other | 12 Cross your arms and give yourself a hug | 13 Take turns to share a happy memory | 14 Find out about the values and traditions of another culture |
| 15 Do something together to support a local charity | 16 Create a collage of things that make you feel happy | 17 Before bedtime, share what has gone well during the day | 18 Introduce a family 'Daily Pause' to be calm together | 19 Create a family wishes jar and take steps to make them happen | 20 Learn a new skill together as a family | 21 Create a kindness box to keep a record of kind actions |
| 22 'Surprise' yourself. Find unexpected ways to move your body | 23 Make a rainbow salad | 24 Smile and say something positive every time you walk into a room | 25 Create a poster highlighting everybody's strengths | 26 Notice the shapes, colours and smells of a new family meal | 27 Make a list of things that have helped you cope with difficult times | 28 Tell someone you love how much they mean to you and why |
| 29 Do something good for the environment | 30 Hold an awards ceremony to celebrate acts of kindness |  <p>"A person's a person, no matter how small"
- Dr Seuss</p> | | | | |

ACTION FOR HAPPINESS



www.actionforhappiness.org

Find out more about the Ten Keys to Happier Living at www.actionforhappiness.org/10-keys

Keep Calm · Stay Wise · Be Kind

Haemophilia Foundation Victoria

A SHOUT OUT to our regional & rural members

The last few years we have been spending the Winter months driving around Victoria on our 'regional visits' meeting up with members on their home turf! It is something we love to do but unfortunately this year we need to...

Stay home and #StopTheSpread

There are still ways to connect with us so check out our website for upcoming online peer support events. www.hfv.org.au

CONNECT SUPPORT EMPOWER



Tell us how you would like to connect... and help shape our future engagement!

info@hfv.org.au

CONNECT

SUPPORT

DURING COVID

EMPOWER



**WE CAN
CONNECT YOU
WITH OTHER
HFV MEMBERS**

email info@hfv.org.au



www.facebook.com/HaemophiliaFoundationVictoria
www.instagram.com/haemophiliafoundationvictoria



REACH OUT...there is a whole community of support for YOU

HFV MEMBERSHIP RENEWALS 2020 - 2021

Your annual membership subscription for this financial year was mailed with your Winter edition of The Missing Factor and was due by the 30th June. Thank you to all those members that have paid your subscriptions to date.

We are aware than many people within our community may be financially impacted by COVID-19. Our committee certainly do not wish add to the burden so for those impacted we will accept membership payments when you are able to do so. **Please note, we still need to receive your completed subscription form for your membership to continue - either via email (there is an electronic version available on our website) or a hard copy mailed to our office.**

As we head towards offering more online peer programs please ensure HFV have your current email address and mobile number by listing them on your renewal form or emailing them to us.

For those who have not been impacted financially by COVID-19, please support HFV by paying your fees and if possible help to reduce the expected shortfall by adding a donation that could help to subsidise other families membership fees.

THANK YOU

We would also like to take this opportunity to say such a huge thank you to all of those members that have made a donation together with their membership renewal. We recognise this generosity at a particularly difficult time with the uncertainty and financial impact of covid for many. Donations are used toward programs that support and assist members. Our committee of management are deeply grateful for all donations received. Thank you for your support.

CONNECT
SUPPORT
EMPOWER



PARKING AT THE ALFRED

When attending the Alfred Hospital for any appointments, please remember to display your disability parking permit at all times wherever you park in and around the hospital.

Also please note there has not been any free parking in & around the hospital for some time.

To avoid a parking fine, please pay the appropriate fee when parking on the street.

Ensure you have your appropriate concession card on hand if asked by the parking inspector.

Any queries, please contact
the HTC social worker(s).

HAEMOPHILIA FOUNDATION VICTORIA INC

13 Keith Street
Hampton East VIC 3195
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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TREASURER Zev Fishman
EXECUTIVE MEMBER Donna Field

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Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | 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 week-end away that included massages, relaxation and meditation. In 2016 twelve 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.
- **YOUTH GROUP**
- The Youth Group aim to meet up during the year to participate in activities like laser skirmish or bowling and lunch. 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**
- The Grandparents and Friends lunch is a great opportunity to connect with all the grandparents and share the company, stories and experiences so please come along and enjoy the day. Lunch is provided by HFV and the company is always good!
- **WE ARE CURRENTLY LOOKING FOR A NEW CONVENOR FOR THIS GROUP. IF YOU ARE INTERESTED PLEASE CONTACT THE HFV OFFICE.**
- **BOYS GROUP**
- Our Boys Toys Day Out is a wonderful opportunity for our boys to get together with other boys with haemophilia or related bleeding disorders and to spend the day with their dad or another significant male in their lives...grandfathers, uncles or family friend.

HAEMOPHILIA FOUNDATION VICTORIA



VIRTUAL
community
ADVENTURE
TRIVIA NIGHT

Saturday 26th Sept
7pm - 8.30pm

JOIN US FOR A FUN NIGHT IN!

THE GREAT RACE TEAM WILL BE RUNNING AN ADVENTURE TRIVIA NIGHT OVER ZOOM! THERE WILL BE BREAKOUT 'ROOMS' SO KIDS CAN BE GROUPEd TOGETHER (AS LONG AS YOU HAVE MORE THAN 1 DEVICE PER HOUSEHOLD) AND OUR YOUTH LEADER 'BLUE SHIRTS' WILL BE LEADING THOSE TEAMS.

IT IS OPEN TO ALL MEMBERS OF OUR COMMUNITY. DO YOU LIVE REGIONALLY? WE'D LOVE FOR YOU TO JOIN US ...SO PLEASE SIGN UP, WE HOPE TO SEE YOU THERE!

BOOKINGS THROUGH TRYBOOKING
WWW.TRYBOOKING.COM/BLGTQ