

THE MISSING FACTOR

What's it like growing up with mild haemophilia?



THE COVID-19 VACCINE
Advice for people
with bleeding disorders

First global summit for
WOMEN & GIRLS with
bleeding disorders

connect • support • empower



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What it means for people with bleeding disorders

DIARY DATES

APRIL

17th April

World Hemophilia Day

Theme: *Adapting to Change*

30th April - 2nd May

Men's Retreat, Lochinver, Carisbrook

See back page for more details

NOVEMBER 2021

19 - 21st November

HFV Community Camp - Lake Dewar

*TENTATIVE BOOKING TBC (due to Covid-19 restrictions)

At this stage we have a **tentative** booking for our annual community camp. This date will be confirmed later in the year. HFV will notify members via email of booking details. If we are able to hold a camp we will be following strict government guidelines around Covid-safe practices.

At this stage no further face-to-face member events have been **booked**, however the committee are considering:

- on-line and in-person focus groups
- a mid year community day
- an activity for people with VWD
- a community trivia night
- Bleeding Disorder Awareness Week walk

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



Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.



PRESIDENT'S REPORT



2021 has finally arrived and let's hope it brings the positive change we are all wishing for. Vaccinations are slowly being rolled out and we thank the Alfred team for a very informative article answering questions you may have about vaccinations for those living with haemophilia and inherited bleeding disorders.

On reflection of the state of global health now I am yet again reminded of the privilege we enjoy in Australia. Without minimising any of the many challenges many of you face daily, I feel that overall the health care available here is in so many ways better than in most parts of the globe. For our friends in Myanmar, family, or friends in the USA or for many others in developing countries I just want to take a moment and acknowledge the solidarity we feel for the life challenges that you are all facing. Having choices about treatment options, vaccinations, and a safe space to speak openly to peers about our experiences and reflections is certainly something to celebrate and embrace. This magazine again highlights so many of these that we may take for granted. Being informed and free to make choices is something I feel I take less for granted now than ever before.

Firstly, I am pleased to announce the housekeeping for committee is well on track. HFV is truly fortunate to have a stable committee yet again and my thanks to everyone for their support. I feel humble to again hold the position of president for HFV and very excited by the executive of the committee being voted at our first meeting in February. Dan Korn will very ably support

the agency as Vice President, Bernard Paes takes on the important task as treasurer and Donna Field provides expertise and a rural voice to executive. There are still spaces available for anyone that may be interested in joining us. We welcome anyone and are very happy to discuss any issues or questions you may have if hesitating because of fear of the unknown.

Many great articles to share and again I thank Julia for her extraordinary ability to continue to produce such a high quality and informative read. From tips on Nordic exercise to increase our balance to reflections on living with mild haemophilia there is something for everyone. Global summit on girls and women with bleeding disorders will no doubt be of interest to many of us as well.

At committee we have had to make very tough decisions as we all have in our work and families. The community camp has been postponed until November. Obviously, the health of our community is always our prime concern so to be cautious is our best defence to the unknown. However, in compliance with COVID restrictions the Men's Retreat will be going ahead at the end of April which is exciting as last years it was cancelled due to COVID.

The committee are hoping to meet face to face in a few weeks as we are desperate to develop our next strategic plan. For those of you who know me I am a tragic for a solid strategic plan as it will be our road map for programs and services we deliver moving forward. If the past 12 months has taught us nothing

else, it has certainly taught us to be flexible and invest in a plan B.

The committee will be considering what may happen in times to come including funding, peer support needs as well as supporting regional and rural community members. Online platforms provide new opportunities but face to face will always be our preferred delivery method and always subject to safety and funding.

As always, I am sure you will enjoy the magazine. As we bravely move into the new COVID normal way of life I am hopeful that there will be opportunities in the not-too-distant future to gather as a community again. In the meantime, the team at HFV are here, at the end of a phone or up for a zoom chat anytime you may need us. One of the many learnings from 2020 is the need we all have for support of others and the need to connect as fellow human beings. Connect, support and empower. Never before have words meant so much than in the times we live now. Be safe and hope to see you soon.

Leonie Demos
HFV President



#RAREDISEASEDAY

28 FEBRUARY 2021

RAREDISEASEDAY.ORG

KEY FIGURES

- There are over 300 million people living with one or more of over 6,000 identified rare diseases around the world, each supported by family, friends and a team of carers that make up the rare disease community.
- Each rare disease may only affect a handful of people, scattered around the world, but taken together the number of people directly affected is equivalent to the population of the world's third largest country.
- Rare diseases currently affect 3.5% - 5.9% of the worldwide population.
- 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative.
- 70% of those genetic rare diseases start in childhood.
- A disease is defined as rare in Europe when it affects fewer than 1 in 2,000 people.

CHARACTERISTICS OF RARE DISEASES

- Over 6000 rare diseases are characterised by a broad diversity of disorders and symptoms that vary not only from disease to disease but also from patient to patient suffering from the same disease.
- Relatively common symptoms can hide underlying rare diseases leading to misdiagnosis and delaying treatment. Quintessentially disabling, the patients quality of life is affected by the lack or loss of autonomy due to the chronic, progressive, degenerative, and frequently life-threatening aspects of the disease.
- The fact that there are often no existing effective cures adds to the high level of pain and suffering endured by patients and their families.

**LEARN MORE ABOUT HOW YOU CAN HELP SUPPORT PEOPLE WITH RARE DISEASES.
GO TO WWW.RAREDISEASEDAY.ORG**



RARE IS *MANY* RARE IS *STRONG* RARE IS *PROUD*

Rare Disease Day is organised by EURORDIS-Rare Diseases Europe and 62 National alliances of patient organisations for rare diseases.

What's it like living with Mild Haemophilia B?



Noah shares his story

Sometimes having mild haemophilia can be lonely because I am different from my friends at school, but also different from my friends at camp.

“

Hi, my name is Noah, I am 13 years old and I have mild haemophilia B. My parents say that I'm special because my condition is so rare. Apparently, only 1 in 250,000 people have this severity of haemophilia B. I also think I am lucky! I have met really cool friends at haemophilia camps, and we have so much fun together. I went to my first camp when I was one and have only missed one camp in all those years.

Living with mild haemophilia B isn't so bad. I have been able to do almost everything my friends have done growing up. However, recently things have started to change. I have had four bleeds in the past 3 years, and because I am not having treatment at home I have to go to the hospital every time I have a bleed.

It has been tricky in the past to know what a bleed was - and what wasn't because I am only mild. There were times that we missed bleeds, like the time I fell off my bed when I was three. Dr Barnes told us later, that 'yes' that was a bleed and 'yes' you should have come in for treatment.

I love sport! I play football, basketball, cricket and go to Little Athletics. This is another reason I am lucky. Dr Barnes tells me to keep playing sport because it is good for my body and keeps me happy.

Due to my more frequent bleeds over the past few years, I will need to begin having home treatment before playing sport. I feel really scared about the needles because I haven't needed to have them much until now. I have watched my friends at haemophilia camp do their own needles and think they are so brave. I hope that I can be as brave as them.

Sometimes having mild haemophilia can be lonely because I am different from my friends at school, but also different from my friends at camp.

I am so grateful to my family and the haemophilia community for supporting me on this journey.

”

SUPPLY & COST OF TREATMENT

...FAST FACTS

Sharon Caris recently participated in an HFNSW information session. A few questions came up about the supply and cost of treatment products, so Sharon thought our community might be interested in reading a few “fast facts” about this topic.

HFA and the state foundations are committed to advocacy for our members to make sure they have the treatment they need so they can get on and live full and independent lives. The information here is mainly about how treatments for bleeding disorders are supplied and funded in Australia, and the cost for governments.

We don't want our families to worry about their treatment, but it is important to understand the basics – especially how to play your part to make sure the system is as cost-effective as possible for governments, so that the system is managed well, affordable and sustainable, and so that everyone in our community has access to appropriate treatment when they need it.

We encourage everyone to work with their Haemophilia Treatment Centre team to make sure they have the information they need about their treatment options and the best way to manage their bleeding disorder. Part of this involves using MyABDR – please do, because it provides important information for you and your treating team.



Here are a few facts for your info!

- We are extremely fortunate in Australia that all Australian governments share the cost of treatment products and they are provided free to the people who need them. In some countries people must pay for their treatment themselves and for many this is unaffordable. In the US, most people must use private health insurance for this, and some “max out” of their insurance each year and are forced to go without the product they need until they are eligible for treatment under their insurance the next year.
- 70% of people with a bleeding disorder around the world receive inadequate or no treatment at all because it is unavailable and unaffordable.
- The National Blood Authority in Canberra purchases blood and blood related products on behalf of all Australian governments (this includes plasma derived factor VIII such as Biostate as well as standard and extended half-life recombinant clotting factors VIII and IX (EHLs) and the new non clotting factor treatment, Hemlibra)
- The Federal government pays 63% and state/territory governments pay 37% of the cost of treatment products for bleeding disorders, so treatment is not only important to each patient and families, but also to your federal and state

members of parliament. Remember that for advocacy!

- In addition to the cost of treatment products governments also pay for hospital services (HTCs), pathology and other medical services required (some of these services are provided through public hospitals; some are provided via Medicare).
- State foundations and HFA advocate on your behalf for best practice treatments for bleeding disorders and are already in discussion with governments about access to some of the new treatments expected to become available over the next few years. Clinical trials for new treatment products and gene therapy may be available to some Australians from time to time – discuss this with your HTC if you are interested to know more.
- New treatment products must first be evaluated as safe and effective by the Therapeutic Goods Administration (TGA) before they can be registered for use in Australia; this process may take one year or more after clinical trials which may also have run for a few years. Before they can be funded, treatment products usually need to be considered by a government committee which will evaluate whether they will be cost-effective and/or better in some way than current products – HFA and individuals can usually have input into this process by explaining the benefits of a new product – for example, in our submission in support of funding for EHLs we explained how EHLs benefit patients - fewer infusions, better vein health, factor stays longer in the body, better adherence to prophylaxis, less joint damage due to fewer bleeds, improved quality of life, less burden on families etc. HFA is concerned these evaluation processes sometimes take too long and we have recently made submissions to governments about speeding this up so access to new treatment is not delayed unnecessarily.
- Information about the cost of treatment products can be found in the National Blood Authority Annual Report – <https://www.blood.gov.au/document/nba-annual-report-2019-20>. The NBA reported that it spent \$656.08 million for fresh blood products and plasma collection and \$614.47 million for plasma and recombinant products in 2019-2020. Clotting factors comprised 13.9 percent of total blood and blood product expenditure. In recent years governments have had some savings because pharmaceutical companies have supplied treatment products for use in clinical trials and for compassionate access programs.
- Australian Bleeding Disorders Registry (ABDR) and MyABDR are critical for ensuring the NBA has the information it needs to purchase appropriate supplies

of treatment products for our community. It is also important for health professionals to see how your treatment is going.

- For demographic and other information about bleeding disorders in Australia see the Australian Bleeding Disorders Registry Annual Report for 2018-2019 <https://www.blood.gov.au/system/files/ABDR-Annual-Report-2018-19-FINAL.pdf>

Data from the ABDR Report 2018-19:

- 6,355 patients
- 5,151 with hereditary Haemophilia A, Haemophilia B or von Willebrand disease .
- 111 with acquired Haemophilia A, Haemophilia B or von Willebrand disease.
- 1,093 with other bleeding disorders.
- 1,804 received product.

We are truly grateful for those who participate in clinical trials and pave the way for others. We always welcome your feedback if you have participated or have experience you wish to share with us. Our strong partnerships with the specialist doctors and other health professionals at our Haemophilia Treatment Centres around the country, with the pharmaceutical industry and with the World Federation of Hemophilia and other organisations around the world, help keep us informed about new treatment developments.

At any time if you have concerns feel free to contact HFA or you are welcome to call me direct on 0410419914 but most importantly always talk with your HTC to make sure you are up to date about what the best treatment is for you or your family member.

Sharon Caris
HFA Executive Director

Thanks to HFNSW for permission to share this article.

FIRST

World Federation Hemophilia Global Summit for women and girls with inherited bleeding disorders

I was delighted to be able to attend the first ever World Federation Hemophilia Virtual Global Summit for women and girls with inherited bleeding disorders. It certainly feels like the voice for women with bleeding disorders is getting stronger and louder and this stand alone summit for women and girls is a huge acknowledgement of the challenges faced and importance of improvements in this field. It is a significant step in the right direction for raising awareness of women with bleeding disorders within the medical profession and the wider community.

These international conferences and summits that I am fortunate to attend provide a stark reminder of how lucky and privileged we are here in Australia with the high level of treatment options available to us compared to those living in less wealthy countries and the opportunities they provide. It is important for us to be the voice and lead the way in terms of best practice care for women and girls with bleeding disorders and set the standard that other countries can strive for.

We still have a way to go here in terms of women realising their bleeding patterns are not 'normal' despite perhaps being normal for them. Education is paramount and that is to ensure women understand their bleeding issues, provide women with educational material so they have the confidence to advocate for themselves and that GPs do investigate potential abnormal bleeding and provide suitable referrals.

All this work will not only increase the voice of women and girls with bleeding disorders but enable diagnosis and treatment in a timely fashion as many women are suffering unnecessarily prior to diagnosis throughout the world.

I'd like to share with you some of the information I learnt from a session titled 'Ask the experts – What do women want?' Andrea James (Consulting Professor

of Medicine - Division of Hematology at Duke University) commenced the session by highlighting some of the themes that had come to light over the course of the summit. This list really highlights some of the challenges faced by the women in our community and by those health professionals who are dedicated to improving the health and quality of life for women with bleeding disorders.

Themes explored:

- Diagnosis for women and girls with bleeding disorders
- Delays in diagnosis from 2-15 years, despite compelling family histories
- Education
- Presence of heavy menstrual bleeding
- Challenges relating to first menstrual period
- Multiple challenges dealing with heavy menstrual periods
- Joint bleeds
- Consequences of bleeding ie anaemia, quality of life, increased procedures and increased hospitalisations

There were also some significant *hope* that had come from the sessions so far.

Hope:

- Combined haematology and OBGYN care, in conjunction with HTC care
- Work at the Foundation for Women and Girls with Bleeding Disorders (www.fwgbd.org)
- Pioneering work of WFH
- The use of digital technology to reach women who may not have immediate access to care
- *This* global summit on women and girls with bleeding disorders

During the session two women shared their experiences of living with a bleeding disorder. Baiba

**women
& girls**
with **inherited
bleeding disorders**

WFH Global Summit

Ziemele, President of the Latvian Hemophilia Society was one and ended her talk with this very poignant reflection. “We are all beautiful, we all matter, our pain is real and our worries are real. We need real support and help at times in our life and what do I want? I want our doctors to listen more and be more compassionate. I want not to be judged as I have this defect in the gene or that I am not severe enough to be helped. I just want to be happy.”

Roseline D’Oiron (Director, Reference Centre for Haemophilia and Congenital Bleeding Disorders, at Bicêtre Hospital AP-HP – University Paris Saclay) shared her experiences with patients stating “not being believed has a huge impact on the quality of life for patients. It is so important that your voice is heard and that we move forward as a shared voice, a movement to improve the outcomes for women and girls with bleeding disorders. We need to be heard, valued and understood”.

Roseline also spoke of the barriers that can delay a diagnosis. Roseline highlighted the need to understand all these barriers in order to recognise them and implement solutions. In this way, we can increase awareness among our health professionals. “Healthcare professionals need to advocate with you and beside you”.

Roseline has summarised this movement perfectly. This voice, for women and girls with bleeding disorders in saying **healthcare professionals need to advocate with you and beside you**. It acknowledges the need for education on both sides, a joint commitment and desire for improvement. A shared journey and challenge to improve the quality of life for our community. The future looks bright but we need to keep our voice loud, strong and ever present.

Julia Broadbent

There are many video recordings available from this summit. To view sessions simply register for the event by clicking on the link below or the QR code.

<https://na.eventscloud.com/ereg/index.php?eventid=577585&>





Important information when visiting

24 February 2021

Dear patients and families,

Protecting our patients who are vulnerable, visitors and staff is more important than ever during the coronavirus (COVID-19) outbreak. To comply with the Victorian Government’s reintroduction of visitors to our hospitals, our visitor’s guideline has been updated to reflect this change.

Effective from Wednesday 24 February, the following visitor restrictions apply at Alfred Health:

General wards

- Maximum two nominated visitors per patient per day within specified visiting hours.

This can be:

- One visitor for 2 hours per day or
- Two visitors each visiting separately for 1 hour - only one visitor with the patient at any time
- Children are permitted to visit, maximum of one child accompanied by one adult per day

ICU

- Two nominated visitors per day from the same household
- Maximum of four nominated visitors
- Visits may now be up to two hours (ensuring physical distancing can be maintained)
- Appointments are required – contact 9076 2000 and ask to be put through to the ICU Visitor Coordinator

Nominated visitors can be adjusted at the request of the patient. If requested, it is recommended that this occurs no more frequently than every 72 hours. If nominated visitors are from different households it is preferred they visit on different days.

Alternatives to visiting such as phone calls and video chat are available. Please speak with your nurse on the ward if you need support with this. Our staff can also provide a care update to a contact person nominated by you, however this may take longer than usual as we are increasingly caring for more patients. Please let your nurse/doctor know if you would like this to occur.

Thank you in advance for helping us keep each other and our community safe.

Thank you for your understanding.

Janet Weir-Phyland
Executive Director, Nursing
Alfred Health



Help us keep our patients safe.








Visitor restrictions

24 February 2021

To comply with the Victorian Government’s reintroduction of visitors to our hospitals, our visitor’s guideline has been updated to reflect this change.

Critically ill, palliative, mental health, children, and patients with a complex disability

- Close family members or significant others only
- Maximum of **one** person at the bedside at one time from 8am-7pm.
- Access is at the **discretion of the clinical team** for visitors to ICU.
- Patients nearing end of life are allowed two visitors at a time, at any time of day

Attending appointments and day treatment areas

The presence of a carer/support person is permitted when the patient requires assistance with communication, wayfinding, mobility, personal care or behaviour management.

Women’s at Sandringham

Birth Suite Patients
One partner or support person
No time limitations whilst in birth suite

Post Natal Wards
One visitor per patient for the duration of two hours

Special Care Nursery
Parents only- Unrestricted visiting

Requirement for special circumstance visitors/carers in all areas

- Do not attend if you are unwell
- Maintain 1.5m distance from patients, employees and others
- All patients/visitors/carers will be required to wear surgical masks, which will be provided upon entrance to the hospital
- Appropriate Personal Protective Equipment to be worn as directed by nursing employees
- Present a permission letter granting access obtained from the nurse manager in the ward you are visiting
- Everyone will be screened on entry to the hospital for signs of COVID-19
- Present to the reception area of the department or ward of the person you are visiting to sign in on arrival, and sign out on departure.



Help us keep our patients safe.






COVID-19

Keep up-to-date with Victorian Government messaging

Home safety plan

Reading and completing a Coronavirus Home Safety Plan can help keep you, your family and friends safe and well.

Key points

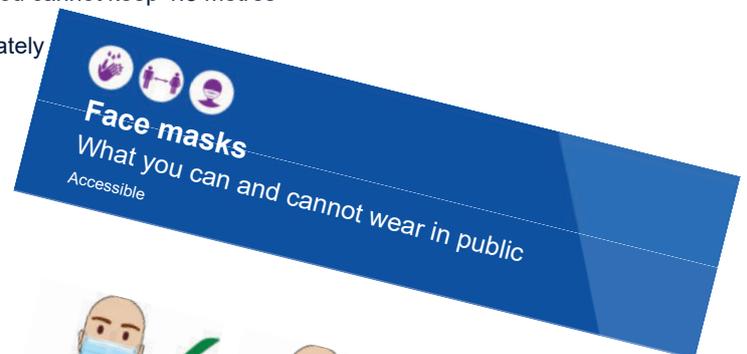
- Reading and completing a Coronavirus (COVID-19) Home Safety Plan can help keep you, your family and friends safe and well.
- The Plan includes important actions you can take inside the home such as regularly cleaning frequently touched surfaces, setting up a COVIDSafe station at your front door and preparing for possible illness.
- Outside the home, the Plan shows how to keep a record of where you have been and who you have seen, tips for wearing a face mask and the COVID Normal steps we need to take to keep each other safe.
- For information on restrictions that apply to visiting friends and family visit social gatherings in [Victoria](#).

Download the [Coronavirus \(COVID-19\) Home Safety Plan \(PDF\)](#) or [Coronavirus \(COVID-19\) Home Safety Plan \(Word\)](#)

The essentials

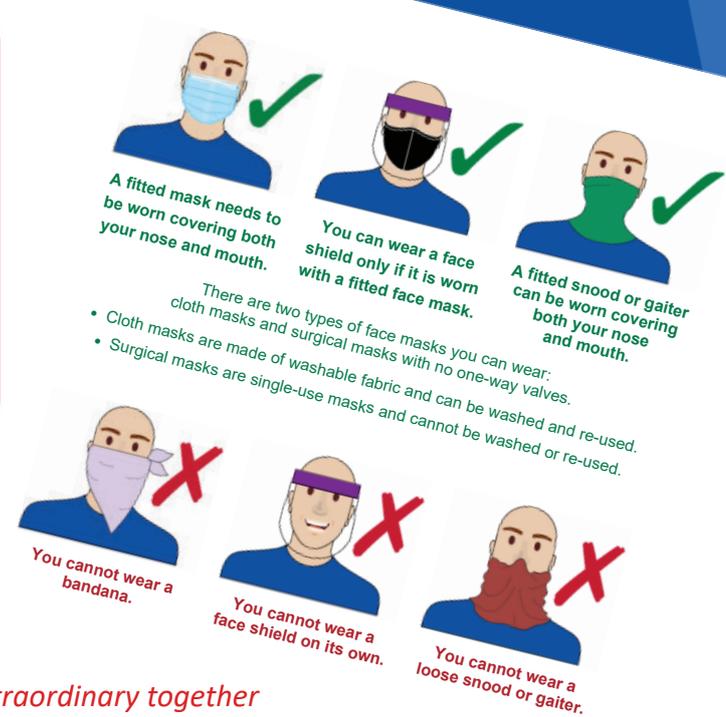
What everyone must do to stay COVIDSafe:

- Practise [good hygiene](#) and regularly and thoroughly wash your hands
- If you're out, maintain [physical distancing](#), keeping at least 1.5 metres away from others
- You must always carry a face mask with you when you leave home unless you have a lawful reason not to.
- It is strongly recommended you wear one whenever you cannot keep 1.5 metres distance from others.
- If you feel unwell, [get tested](#) and return home immediately
- Cough and sneeze into a tissue or your elbow
- Outdoor activities are safer for everyone



Keep up-to-date
with any changes

www.coronavirus.vic.gov.au



RCH TEACHER SEMINAR 2021

This year the Royal Children's Hospital HTC team held their annual teacher seminar as a live on-line seminar. Congratulations to the team for providing such an informative session to not only educate the teachers but also increase their confidence and ability to provide the right support for our boys.

I was delighted to have been invited to speak at the seminar about the role HFV plays in providing peer support for people with bleeding disorders in Victoria. I was also very impressed to hear the 4 boys (Harry, Lachy, Callum and Fefe) that spoke and answered the teachers questions very honestly and succinctly about their experiences with haemophilia. This really helped to shape our understanding of the impact of haemophilia and were an invaluable resource for the teachers listening.

If any of your children's teachers didn't manage to attend the seminar the session was recorded and is available to view on our website (or through the QR code here).
www.hfv.org.au/publications/local-resources-publications

Here are some of the questions that came up in the session that were answered by the boys and their parents.

How difficult was it to transition from a port to vein treatment?

Harry: Well the haemophilia camps kind of helped me with it because I was never really keen on doing it (vein treatment). Then I went to the camp and saw Lachy and all the older boys doing it and I went back the next year and I did it the first time and it got easier from there.

Do you mind other students knowing about your haemophilia?

Lachy: No, most of my close friends know and I think it is good for them to know so then if something does go wrong then they know. And I see it as just a part of me so I've got nothing to be ashamed about so I can just tell them.

Catherine (Lachy's mum): Lachlan wears a medic alert around his neck and when he was in prep he had a lot of questions asked from other students about why he was wearing it and the way he overcame that was to do a show and tell about it. So therefore everyone in the class knew why he was wearing something around his neck and the reasoning behind it.

Do you boys know when there is something wrong?

Fefe (in prep): On my first day of school my toe was hurting and I couldn't even walk. I told my teacher. I put ice on it and rested.

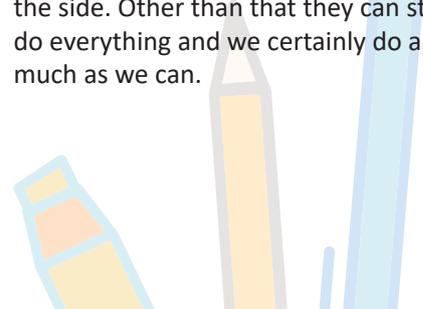
Fernando (Fefe's dad): Fefe woke up really sore on his toe and he told me straight away so the first thing I did was give him a dose of factor VIII before school. I sent him to school because it wasn't swollen but then he complained about it a little bit. The good thing is he recognises if it's too painful and if it's a concern he knows what to do.

What expectations do you have from the teachers for your boys?

Fernando (Fefe's dad): I think it is just about managing it and listening to them, the way they express themselves. My boy is only 6 so the older boys can express themselves better. Just give us a call and we can try to deal with it better than anyone else. But you've got to treat them like normal, it is part of their life and they understand that. And not to panic.

Catherine (Lachy's mum): The best thing is to not try to single them out, they are normal boys, don't hold them back. If they want to give something a go, let them go. They are no different than any other little boy and they will tell you if something is wrong. Don't wrap them up in cotton wool, let them be who they are. Lachlan has thrived through his schooling just being him.

Naomi (Callum's mum): To really make sure you listen to them if they say they are in pain or if something is bothering them. Make sure they are listened to and heard and make sure they are treated like any other child. I don't like them to be seen as different, they are just who they are, they just have this additional little thing on the side. Other than that they can still do everything and we certainly do as much as we can.



Have you heard of NORDIC WALKING?

At HFV we are always interested to hear about any activities that may help keep people physically active. Nordic walking stood out to me as it adds the stability of poles to the activity of walking and that could certainly be beneficial to some members of our community particularly if they have mobility issues and/or balance issues.

We contacted Abi Polus, a haemophilia physiotherapist from Alfred Health to get her thoughts on Nordic Walking and here is what Abi had to say:

This activity may offer people with mobility issues benefits of exercising (musculoskeletal, cardiovascular, mental health, to name a few) with an increased peace of mind that the extra stability from the additional two points of contact with the ground (the poles) will provide.

This is not an activity that will increase internal proprioception and stability and we would encourage a program with your physio to address stability issues.

We would always encourage a check with your GP or HTC and your physio before starting any new exercise regimes.

Abi Polus
Physiotherapist
Alfred Haemophilia Treatment
Centre



FOR HEALTH FITNESS & WEIGH CONTROL

Whether you want to maintain good health, improve your fitness or wish to reduce your weight, Nordic Walking is a great alternative to other forms of aerobic activity.

Aerobic activity is an important part of maintaining good health, improving fitness and reducing weight. Most health organisations around the world suggest that 30 minutes of moderate aerobic activity a day at least 5 days a week can significantly reduce the risk of lifestyle illnesses such as cardio vascular disease and stroke. They also recommend at least 45-60 minutes a day at least 3 days a week if you want to improve fitness or reduce weight.

Walking is a great, moderate intensity aerobic activity enjoyed by most people. Imagine being able to boost the aerobic value of your walk by as much as 45%. Nordic Walking can help you do that.

The use of Nordic Walking poles combined with the correct technique engages the upper body muscles when walking and increases the use of lower body muscles. Research consistently shows that this leads to an increase in oxygen uptake, increases heart rate by 5-17 beats per minute and burns up to 45% more calories than a regular walk.

And the good news is that research also shows that Nordic Walking requires less effort than regular walking. A 2009 study also found that Nordic Walking at 7.7 km/h produced similar results to running

at 9.8 km/h and is considerably easier on joints.

By Nordic Walking, you can get the same aerobic value in a lot less time or get a lot more value for the same effort compared to regular walking.

FOR REHABILITATION

If you are recovering from injury or surgery, have a condition such as Parkinsons, MS, Arthritis or a chronic disease, walking can be difficult. This in turn can lead to being less active and mobile than you would prefer.

Nordic Walking may help. Using Nordic Walking poles combined with the correct technique reduces pressure on the lower body, making walking a lot easier.

By using the upper body when walking, the load is spread across more muscle groups and enables you to take a longer stride. Nordic Walking also helps to promote correct gait and posture and improves stability.

The regular, alternating arm swing used when Nordic Walking also promotes an increased "torso rotation", which has proven to be beneficial for relieving muscle tension. Making walking easier may just encourage you to be that little bit more active, mobile and healthy.

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Nordic Walking Australia
www.nordicwalkingaustralia.com.au*

BE AWARE OF THE SYMPTOMS OF COVID-19

If you have any symptoms, please get tested.



Australian Government

BE COVIDSAFE

COVID-19: Identifying the Symptoms

Symptoms		COVID-19 Symptoms range from mild to severe	Cold Gradual onset of symptoms	Flu Abrupt onset of symptoms	Allergies* May be abrupt or gradual onset of symptoms
Fever		Common	Rare	Common	No
Cough		Common	Common	Common	Common (asthma)
Sore Throat		Sometimes	Common	Sometimes	Sometimes (Itchy throat and palate)
Shortness of Breath		Sometimes	No	No	Common (asthma)
Fatigue		Sometimes	Sometimes	Common	Sometimes
Aches & Pains		Sometimes	No	Common	No
Headaches		Sometimes	Common	Common	Sometimes
Runny or Stuffy Nose		Sometimes	Common	Sometimes	Common
Diarrhoea		Rare	No	Sometimes, especially for children	No
Sneezing		No	Common	No	Common

Adapted from material produced by WHO, Centers for Disease Control and Prevention and the American Academy of Allergy, Asthma and Immunology. *Respiratory allergies include allergic rhinitis (hay fever), and allergic asthma. Other common symptoms of hay fever include itchy nose and itchy, watery eyes.

It is very difficult to distinguish between the symptoms of COVID-19, influenza and a cold. If you have any infectious or respiratory symptoms (such as a sore throat, headache, fever, shortness of breath, muscle aches, cough or runny nose) don't go to work. You need to self-isolate and to be assessed by a medical professional. You may need testing for COVID-19. You must not return to work until cleared by a medical professional. You need to ensure that the people you care for are protected and safe. People who have respiratory allergy symptoms such as allergic rhinitis (hay fever) and allergic asthma should stay home and get tested for COVID-19 at the onset of their symptoms and if they experience symptoms that are unexpected, seem different or worse than usual, or do not respond to their usual medication.

For more information about **Coronavirus (COVID-19)** go to health.gov.au
Visit www.health.gov.au/resources/translated or for translating and interpreting services call 131 450.

DTD70007045

Q & A

*With HFV Patron, Dr Alison Street AO
& HFA Executive Director, Sharon Caris*

A transcript
from our
recent AGM

Necessity is the mother of invention - a need or problem encourages creative effort to meet the need or solve the problem. Not a new idea but seldom has it seemed more relevant for society than over this past year living and dealing with Covid-19. Individuals and families have met with significant challenges even roadblocks at times managing their daily lives let alone a health condition. Organisations too, both small and large have been affected. At HFV where much of our work is based around in-person engagement with our members, Covid has been especially challenging.

But there have been 'wins' too, surprising, unexpected, changes for the better, changes that will be here to stay. Moving the AGM to a virtual setting on zoom was one such change and "Covid win" for us. Not only did the virtual platform open the event up to our entire community: members, supporters, and funders alike regardless of location or ability to travel - but it also created an opportunity to hear from two wonderful guest speakers, HFV Patron Dr Alison Street AO and HFV Executive Director Sharon Caris.

How incredibly fortunate we are to have two such extraordinary individuals as part of our community. Not only agreeable but appreciative of the opportunity to be part of the AGM. Both women share a long work-life history dedicated to improving health outcomes for the bleeding disorders community. Speaking at the AGM these amazing ladies shared with us some fascinating and frank insights into their respective journeys and spoke about the challenges they foresee and the hopes they have for our community moving forward.

For those who missed this unique experience, HFV is pleased and proud to be able to share now a little of what Alison and Sharon shared with us all on the night. I encourage you all to take a moment out to read.

Andrea McColl
Executive Assistant

Q: What is your connection to the bleeding disorders community?

A: Sharon

It's a real honour to join your meeting tonight. I think it is even more of an honour to join Alison as she is a person that I deeply respect. I wanted to tell you just a little bit about my background. I've been the executive director at HFA since Jenny Ross retired in 2001. It was pretty obvious when I met Jenny and did a little bit of reading that Jenny was irreplaceable. I'd had no personal or work experience of haemophilia or a bleeding disorder or the organisation but I became quite fascinated when I saw the job advertised and met the HFA board

at an interview, I realised just how complex it can be for families. I learnt more about the traumatic history of course and I could immediately see just what the community was like and how it had evolved. There was so much resilience and determination to make life better for the people affected and such a sense of optimism as well, but also a view that the past could not be overlooked.



So much had been achieved and so much learnt from the history I knew it would be a challenging role and I became fascinated and I was hooked.

I find everyday just as stimulating and important as those early days at HFA and I think it is because of people like you. I've learnt a lot and I keep learning.

A: Alison

I trained as a haematologist after medical school in Melbourne, Sydney and Boston in the US and while I was in Boston in the early eighties I was hearing about GRID (Gay Related Immune Deficiency), and starting



to read a little bit about it but nobody really took it terribly seriously until Bruce Evatt from Centres for Disease Control in Atlanta brought to the attention of the world, against a lot of the pharmaceutical companies, against a lot of the haemophilia treaters wishes to do so, that this was an infection that had already been transmitted by blood and was present in the concentrates which people with haemophilia were infusing. So I came back to Melbourne and I didn't know very much about haemophilia and even less about HIV, it wasn't even called HIV in those days and nobody knew very much about it. I was looking for a job as a haematologist and Ron Sawers had retired about 18 months before I got back.



Henry Ekert was working at the Royal Children's Hospital. I applied for the job at The Alfred and I met with Henry. We immediately became fast friends and in fact share a birthday so Henry and I have a lot in common and I have a lot to thank him for. I was at The Alfred from 1986 until 2012 and the things that I saw and the things that changed were just remarkable and I met many, many fantastic people along the way. Everyday was different.

Q: What has been one highlight in your long and extended careers working with the bleeding disorders community?

A: Sharon

It was a real struggle to get governments to fund recombinant treatment products in the early 2000s. HFV had been pivotal in getting access for kids in the mid 1990's but for adults it was a very different kettle of fish. We knew we still needed plasma derived products for some people with haemophilia, for people with VWD, for people with inhibitors and we didn't want to throw the baby out with the bathwater obviously. We knew plasma derived products were much safer than they had been at the time of HIV and Hepatitis C but we were concerned about future safety and supply and where risks could be avoided and we didn't want to have people put at risk. Variant CJD (mad cow disease) emerged and there were fears globally that this might get into the blood supply and so that was the pivotal point that helped the push.

I don't naturally like playing politics and this whole affair was very political and it was very difficult. But I do remember a fantastic call from the ministers office to tell me that they had finally agreed to fund recombinant for everybody. And it wasn't my win, it wasn't my win at all but I was just relieved that the advocacy of HFA over a period of time and other people too within government and the medical fraternity had really meant this had come to a positive outcome. It also signalled that the pressure on both safety and supply was relieved as we moved forward. So that was one of my highlights as it was such a

positive outcome for the community.

A: Alison

As Sharon said, this was an extremely long struggle to achieve funding for recombinant factor and we first got it in 1996. It must have been a very slow news day as I am on the front of the Australian newspaper infusing a young man. He was the first person to receive recombinant factor in Australia and we had taught him how to self infuse the week before.

So this lad was 13 at the time and terribly cute, I said, 'should I infuse for you?' and he said 'no I'll do it' and he put the needle in with this wonderful recombinant bottle, the very first time we'd had it in Australia and all the cameramen fainted! This kid was so calm and cool I was so proud of him.

I'm very pleased of the acknowledgement we were able to make at the Alfred of Ron Sawers by calling the centre after him - The Ronald Sawers Haemophilia Centre and the Children's said they would like to follow that and called their centre the Henry Ekert Haemophilia Centre. I think that acknowledging Ron was important for us because he cofounded the Haemophilia Society of Victoria, later HFV, back in the 1950's as a support for the parents of children with haemophilia whom he had been able to diagnose with laboratory testing. He had brought back from his studies in the UK the coagulation testing skills and knowledge of the clinical aspects of bleeding disorders. It was just wonderful that we were able to also celebrate with him a special symposium of fifty years of haemophilia care at Alfred.

And a final highlight was to be invited

to be the Patron of HFV because it keeps me connected to the community.

What do you see as the main challenges moving forward in people's healthcare?

A: Alison

We have had amazing progress in the treatment of HIV which is now a chronic disease, we still see some long term problems of treatment but we are not seeing further infection within our group. That was a very difficult phase for so many people and showed what a very resilient and quite extraordinary community we have.

It is really important now in the days of plentiful safe product, and might I just be a little bit provocative and say I think we almost have too much at times, but I think it is so important that there are holistic funding models set up for haemophilia care that includes the proper opportunity for patients to receive clinical care as well as clinical product. I think we've got to be very clear on that and it's so important for people to engage in their treatment and care.

We want people to get the best outcomes with the physical treatment and products they have. There is plenty of product in Australia now and we've got to make sure that supply quantity and choice is maintained and I wouldn't take my eye off it at all.

And with the amount of product infused we want to know what sort of social and physical wellbeing outcomes we are getting. We want people to be able to recognise what is the best way they should be receiving the product.

Hemlibra takes a completely different path in all of this because it's going to be such a game changer for many people but even with Hemlibra we'll still need to be assessing how people

are responding. Are there better ways in which their product is individualised for them? Some people don't want to go onto Hemlibra. They need to have proper pharmacokinetic testing to see what is the bleed rate on a particular product. Can you, for the same amount of product or even less at times just given at a different frequency and dosage at those times, achieve better outcomes?

It's a vital matter of collaboration that everyone is actively linked with their (HTC) centre to stay connected, to keep working with the doctors and nurses and the physiotherapists in particular, to monitor physical progress. Equally important is to stay connected with nurses and social workers to know exactly what is going on in the mental health space because that again is something that I would see as even more critical now post covid, with isolation and we have got to really look at that very carefully.

I would like to see resources really strengthened to make sure that is happening within our community.

I echo what's been said about hepatitis C. It has taken a long time to get excellent treatment for Hepatitis C. Many people with long term infection have liver scarring, you might control the virus but the scarring is still there and that needs continual monitoring through Hepatitis clinics and I think that is an important message.

The (recent) HFA document on ageing is a fantastic document and it will be internationally recognised and adopted. It is a great credit to HFA. Ageing becomes a really important issue for our community. Our centres are going to need to source additional services such as from gerontologists, we need all sorts of support for a whole of life integrated care model that taps into the expertise of people we never thought of or contacted before, we didn't need them before because partly we didn't recognise

the issues they could help us with but also we didn't have the resources and we didn't have the time we were just so pressed with other issues. Those issues have now been replaced with the issues of ageing and the mental health issues. That is the way I see forward at this stage.



HFV COMMUNITY CAMP 2021

In adherence with COVID regulations and safe practice our HFV committee are constantly reviewing the viability of running face to face member events.

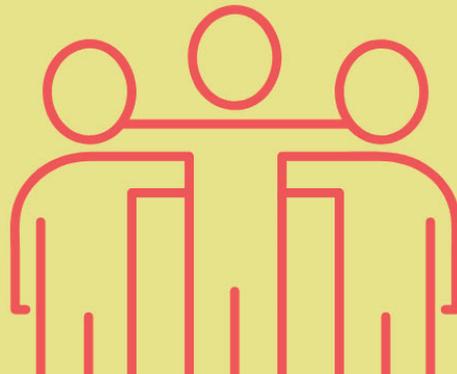
Despite our best hopes for our Community Camp to be held in March our committee made the decision to post-poner the event. The uncertainty of participant numbers for accommodation, recent hotel quarantine outbreaks and potential for further restrictions meant that holding a camp in March was not a viable option.

We are however delighted to announce that we have a new date booked for November with the hope that we will be in much better position with covid restrictions and should be able to run a full covid-safe program.

Lake Dewar YMCA Myrniong (near Bacchus Marsh) 19th - 21st November 2021

HFV will be very mindful of all the Covid-safe recommendations around our camp activities as will the camp staff and our program will be adjusted accordingly.

Please ensure we have your correct email address by sending any updates to info@hfv.org.au. The camp registration forms will also be available on the website.



What is positive psychology?



Mental health is defined as 'a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to her or his community' (World Health Organisation, 2010).

Bearing this in mind, here is an interesting article from Black Dog Institute looking at the benefits of 'positive psychology'.

What is positive psychology?

Traditionally in psychology, the focus has been on identifying and treating mental health problems such as depression. This is critically important for those facing mental illness however, it provides an incomplete picture of mental health.

Positive psychology is a relatively new branch of psychology that shifts the focus from what is clinically wrong, to the promotion of wellbeing and the creation of a satisfying life filled with meaning, pleasure, engagement, positive relationships and accomplishment.

Gable and Haidt (2005) defined positive psychology as "the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions."

Positive psychology is not about putting on a happy face all the time. Life can be hard and disappointments and challenges are inevitable. However, scientific research has shown that

there are some strategies and skills that allow people to navigate the challenges of life more effectively and enjoy life despite the upsets.

Practical strategies to increase your psychological wellbeing:

1. *Enhancing pleasure*

Savouring is the awareness of pleasure and of giving deliberate conscious attention to the experience of pleasure. Fred B. Bryant and Joseph Veroff of Loyola University have identified five techniques that promote savouring:

- Sharing with others: seek out others to share the experience and tell others how much you value the moment. This is the single strongest predictor of the level of pleasure.
- Memory building: take mental photographs, or even a physical souvenir of the event, and reminisce about it later with others.
- Self-congratulation: don't be afraid of pride; tell yourself how great you are and remember how long you have waited for this to happen.
- Sharpening perception: focus on certain elements and block out others, like closing your eyes and listening to the music.
- Absorption: allow yourself to become totally immersed and try not to think, just sense.

Avoid forming habits

Rapidly repeated indulgence in the same pleasure does not work. Neurons are wired to respond to novel events, and not to fire if the events do not provide new information. Seek out a variety of experiences and spread out pleasurable events over time. Surprise yourself or others with small presents of pleasure.

2. *Engagement*

Mindfulness: Mindlessness pervades much of human activity. We act and interact automatically, without much thinking. Mindful attention to the present moment can be developed through meditation and mindfulness based therapies.

Through mindfulness we can focus our perspective and sharpen our experience of the present moment.

Nurture relationships: Your income level has a surprisingly small effect on your psychological well-being. The most fundamental finding from positive psychology is that strong personal relationships have the greatest impact on your satisfaction with life. Make sure that you invest time and energy in your friends and family.

Identify and use your strengths:

Think about your personal strengths and how you might use them in your everyday life. Are you a leader, playful, fair, curious or original? Do you have a good sense of perspective? Do you love learning? Are you genuine? Are you good at teamwork?

If you have internet access you can take an online test on Martin Seligman's website (www.authentichappiness.org) to explore your personal strengths. Cultivate and use your strengths at work, in family life and in your leisure time.

Seek out 'flow' experiences: Through his research, Mihaly Csikszentmihalyi sought to understand how people felt when they most enjoyed themselves and why. He developed the concept of 'flow' which describes a state of joy, creativity and total involvement. Problems seem to disappear and there is a feeling of transcendence. 'Flow' is the way

people describe their state of mind when they are doing something for its own sake. Some activities consistently produced 'flow' such as sport, games, art and hobbies. Csikszentmihalyi has identified the ingredients to creating these optimal experiences:

- the task is challenging and requires skill
- we concentrate
- there are clear goals
- we get immediate feedback
- we have deep, effortless involvement
- there is a sense of control
- our sense of self vanishes
- time stops

Csikszentmihalyi says work and family life can provide important opportunities for 'flow'. When people were in 'flow', either at work or in leisure, they reported a much more positive experience.

When challenges and skills were both high, people felt happier, more cheerful, stronger and more active. They concentrated more, felt more creative and satisfied.

3. Finding meaning

Keep a gratitude diary: Take the time each day to write down three things that went well and why. This causes psychological well-being levels to increase in a lasting way.

Thank a mentor: Write a letter of thanks to someone to whom you owe a debt of gratitude such as a teacher or grandparent. Then visit the person and read the letter to them. People who do this are measurably happier for more than a month.

Learn to forgive: Let go of anger and resentment by writing a letter of forgiveness to a person who has wronged you. Inability to forgive is associated with persistent rumination.

Weigh up your life: Take time out occasionally to consider how you are going in the major facets of your life such as family, work, finances, health and play. Reflect on the progress you are making in working towards your

major life goals.

Make changes in your life to match your priorities

Perform small acts of kindness: Performing five kind acts a week, especially all in one day, creates a measurable boost to levels of psychological well-being. Giving not only makes you feel good about yourself, it enhances your connection with others and can bring you positive feedback from others.

These and other strategies are detailed in Martin Seligman's book *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment*.

Useful Websites

Centre for Confidence and Well-being, Scotland
www.centreforconfidence.co.uk

Positive Psychology Institute, Sydney
www.positivepsychologyinstitute.com.au

The Positivity Institute
www.thepositivityinstitute.com.au

The University of Pennsylvania, Positive Psychology Centre
www.ppc.sas.upenn.edu

Time Magazine: The New Science of Happiness.
www.time.com/time/2005/happiness

Six Part BBC Series: The Science of Happiness.
http://news.bbc.co.uk/2/hi/programmes/happiness_formula

For more resources please go to www.blackdoginstitute.org.au



ASK US

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

COVID-19 VACCINE & BLEEDING DISORDERS

We have all heard that exciting news that the first vaccine has arrived.

1. What does it mean for people with bleeding disorders?
2. Are there any special instructions for people with bleeding disorders?
3. What will having a vaccine be like?
4. Should I still have the fluvax?

1. What does it mean for people with bleeding disorders?

The vaccine is recommended for people with bleeding disorders and depending on the vaccine rollout you should be contacted when it is your turn to have a vaccine. People with bleeding disorders are not at any increased risk of getting COVID or having complications if they do get COVID, so will be alongside most of the population in terms of when they will be vaccinated. For advice about the rollout please see the following website for more information <https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines>

There is no evidence that the vaccine will cause you harm if you have a bleeding disorder, HIV, Hepatitis, or are on steroids or another immunosuppressant medication related to your bleeding disorder.

Both covid vaccines currently

approved in Australia require 2 intramuscular injections scheduled 2 weeks apart for full vaccination; they cannot be given subcutaneously like the Fluvax.

As the vaccine is given into the muscle, patients who have severe or moderate haemophilia should have factor replacement treatment prior to having the vaccine. Plan to have your prophylaxis dose on the day of the injection to avoid extra factor. People who are on the new treatment emicizumab (Hemlibra) do not need to have any additional treatment prior to having the vaccine. As the injection is intramuscular people with bleeding disorders are advised to contact the Haemophilia Treatment Centre, if possible when they are advised they are coming up for covid vaccination to discuss if any additional treatment will be required and if so the dose. This may be different for each person.

2. Are there any special instructions for people with bleeding disorders?

Where possible a smaller needle is used to give the vaccine, such as a 23- or 25-gauge needle. Pressure should be applied for at least 10 minutes after having the vaccine. Rubbing the area should be avoided. Ice can be applied to the area afterwards for a 10-minute period and may be useful. After having the vaccine you should perform a self-check and palpitation to look for any haematoma. It is recommended that this self-check be repeated 2-4 hours after the injection.

If there is discomfort in the arm for 1-2 days after the injection is not alarming, unless it worsens or is accompanied by swelling. Anything of concern should be reported to the Haemophilia Treatment Centre.

3. What will having a vaccine be like?

You can read this article from the New York Times about experiences of having the vaccine. <https://www.nytimes.com/2020/12/28/us/vaccine-first-patients-covid.html>

4. Should I still have the fluvax?

Flu Vaccine: Current advice is that people should still have a Fluvax this season as well as the COVID vaccination. The flu vax should be given separately and at least 2 weeks prior to the complete covid (2 doses) vaccination or 2 weeks post the covid vax.

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

References

Covid -19 Vaccination guidance for people with bleeding disorders. The World Federation of Haemophilia, EAHAD, EHC, NHF <https://news.wfh.org/covid-19-vaccination-guidance-for-people-with-bleeding-disorders/>

<https://www.nytimes.com/2020/12/28/us/vaccine-first-patients-covid.html>

HFA document <https://www.haemophilia.org.au/publications/news/covid-19-vaccine-faqs>

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 straight forward 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

CONNECT

SUPPORT

WE CAN
CONNECT YOU
WITH OTHER
HFV MEMBERS

EMPOWER

DURING COVID



email info@hfv.org.au



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



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



Alfred Health has recently introduced a **Patient Portal** that allows you to access your Alfred Health Medical record, anytime, anywhere!

What can I view on my Patient Portal account?

- View upcoming appointments
- View pathology results from tests conducted at the Alfred Health pathology laboratory (14days after a final result has been determined), excluding anatomical pathology and genetic testing
- View letters sent to patient or to referring external providers
- View inpatient Discharge Summaries, medication lists & Nursing / Allied discharge summaries
- Receive secure message from your clinicians
- Registering for Alfred Health's Patient Portal
- Existing Alfred Health patients can sign up to the Patient Portal online by following the instruction below.

Registration is available between **Monday - Friday, 8am - 4:30pm.**

To register, you will need photo ID (such as drivers licence, student ID, passport).

Once you have your ID ready, you can register here which will allow you to join a virtual queue and connect you with our Patient Portal support staff.

You will then be asked your full name, date of birth and home address. You will need a camera and microphone to complete your registration.

Want to learn more?

Please go online and visit AH connect for patient brochures, FAQ's and details on **how to register for the Patient Portal**

Alternatively, you can telephone or email our friendly Patient Portal Support team. Call (03) 9076 5000 or email patientportal@alfred.org.au

We look forward to welcoming you to the **Patient Portal!**

HFV COMMUNITY
RECONNECT 2021

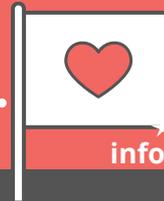
LOOKING BACK & RECONNECTING

Re-connecting old friends
and acquaintances

HFV will be organising opportunities to reconnect our community. Did you go to camp in the 80's, were you on the HFV committee in the 60's? Was your family connected with HFV and have lost touch with others?

We have a unique history with many people crossing paths in both challenging and supportive times and some have lost contact along the way.

It may be as simple as wanting to know how an old acquaintance is doing or maybe the opportunity to reminisce over old camp photos together.



Email info@hfv.org.au and register your interest and we'll be in touch!

info@hfv.org.au

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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VICE PRESIDENT Dan Korn

TREASURER Bernard Paes

EXECUTIVE MEMBER Donna Field

GENERAL COMMITTEE:

Cara Gannon

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Erika Mudie

Claire Brunet

Chris Phong

**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

Ronald Sawers**Haemophilia Treatment Centre**

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

Professor Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Kara Cordiner | Haemophilia Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | Physiotherapist
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 2019 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.



2021 MEN'S RETREAT



Enjoy a weekend of relaxation

- massage
- meditation
- mindfulness

Free food & accommodation

HFV have everything covered so you just need to pack a bag and you're set

Where & when

Lochinver Lodge,
Carisbrook
30th April - 2nd May
(subject to covid restrictions)

Please contact Zev Fishman on
0419 552 695 to make your booking
or contact HFV at info@hfv.org.au

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