

THE MISSING FACTOR

Life in lockdown

COVID-19 updates

Looking after your veins



connect • support • empower



WINTER 2020

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DIARY *DATES*

JUNE

- 20 Community Trivia Night (online).
See page 9 for further details.

Over the next few months...

HFV will be offering online facilitated & FUN peer support sessions including:

LADIES NIGHT IN

MEN'S NIGHT IN

YOUTH NIGHT IN

DATES ARE YET TO BE CONFIRMED - please check our website and Facebook page for dates and more details. We will also aim to send targeted emails to potential attendees.

We hope to run more online sessions during this time of social distancing and also into the future to make peer support more accessible for our regional and rural members.

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

What a year we are having! No one can accuse our life of being same, same in 2020. We started with devastating bushfires and now a pandemic and a lockdown as we have never experienced before. 2020 will certainly be one to remember and reflect in years to come to future generations 'I remember when...'

Like the rest of the world, at HFV we have been trying to adapt to our new world and pivot our peer support programs into our online world we are now all entrenched in. In recent years we have been discussing our membership engagement strategies and looking at ways to engage with our community online and effectively. One thing that COVID-19 has done is make us put into action plans we may have had sooner rather than later.

Stay tuned for what is to come. We are investigating new and exciting ideas on ways to communicate and continue to connect, support, and empower. With all our face to face peer support programs on hold for now we are trying to engage with everyone in a way that works for you. We are all learning as we go in these times. What are challenges are actually exciting in the opportunities we now have to explore with your support. Watch this space and please support us in this work as we invest in the brave new world forced upon us.

As we all stay home more than ever before it is a great time to enjoy the winter edition of our magazine. So many interesting articles and bursting with so much information. Lots of tips on how to improve your safety in these times including physically, mentally and online presence.

Join us for a fun night of trivia. No cheating with Dr Google but step up for the challenge and join the fun. Booking details are included. Many

thanks to Tim from Purple Soup for stepping up and offering opportunities for us to engage despite the lockdown.

As always HFA provide some useful information to support our community. Worth a read. Sharon and the team have also adapted the way they are working but as always have not missed a beat in the support they provide to all the state foundations as well as our health professional key networks and international connections. Great work as ever and thanks again for the HFA team not only for the article but their support and guidance on moving into a social media world.

Internationally it is with sadness that the World Congress has been cancelled. I was intending to attend this year which would have been an amazing opportunity for HFV. Sadly, it is not to happen. However, all is not lost. There is an amazing opportunity to join in the discussion in a virtual summit from June 14-19. These sessions will be free to everyone in the bleeding disorder community. There are some details in the magazine. Well worth trying to participate in some of these sessions. I know I will be dragging myself away from my addictive TV streaming to learn from the experts in the world doing amazing work to support our global community.

Great to read the reflections of the impact of COVID from some of our community. Many thanks to our Patron, Prof Alison Street for taking time to share her thoughts during these times along with others. To all at the HTCs we are so grateful for the ongoing support. I am sure their lives have had to adapt more than most of us with arrangements always in the pipeline for an increase in the numbers of those affected by COVID. We thank you for your efforts and wish you best of health to you and your families. Extra thanks to our



social workers at the Alfred for the great articles for us to enjoy.

Again, our team Andrea and Julia have done a fabulous job adapting to the needs of our community. This edition is particularly well appreciated. Julia has extended the content with so much useful information to not only us but our extended families. Information on our mental health from Beyond Blue is important reading as we are all hopefully practicing good self-care. The tips on staying safe online for our children and the training available free for those not that confident with technology through the Be Connected program are also important resources to share with you all. ES-safety Commissioner has many useful resources for educators, parents, and seniors with tips on safety and some traps to be aware of as we rely online as our only communication tool in lockdown.

As a tiny team at HFV we want to acknowledge the hard-working staff again. When you are tiny in structure and funding, changing everything in your business delivery so quickly has had its challenges. We thank the support of their families as well. Both Julia and Andrea have worked tirelessly to adapt the core business to make sure we have not missed a beat as an agency from meeting our legal requirements and also being as accessible as possible for our community.

Victoria is moving into a gradual ease of some restrictions, but I think we all know there is still a long path

ahead. Life will continue to look different and we will all need to continually adapt to the needs of others as we go. I do want to stress that although the media and our lives feel so full of COVID news, numbers of affected and all the restrictions we must always all keep our eyes focused on our other health issues. There have been disturbing trends that people with chronic illnesses are not seeking medical support when they need to as part of fear of accessing health services. Our bleeding disorders are still very real and still what we need to be attentive to is our own or our loved ones needs as always. Please stay in touch with your health team, look after your overall health including your bleeding disorder. At times of other demands, it is easy to minimise our ongoing health needs. Caring for your haemophilia or VWD is as important now as always so please don't ignore your other health needs. Precautions are critical for us all in minimising the chance of contamination of COVID but you matter and you still need what you need. Your health professionals continue to support you as do we at HFV so please seek support as you may need.

HFV are ever evolving as we all are in these times of our new world. No matter what restrictions we may face we are always one email or a phone call away from you. Connect, support and empower remain our goals we are just adapting the way we deliver these to respond to you as our community. Stay well. Stay safe. Stay home when you can but just as important to us is stay connected.

Leonie Demos
HFV President



World Health Organization

Are people living with HIV at increased risk of being infected with the virus that causes COVID-19?

People living with HIV with advanced disease, those with low CD4 and high viral load and those who are not taking antiretroviral treatment have an increased risk of infections and related complications in general. It is unknown if the immunosuppression of HIV will put a person at greater risk for COVID-19, thus, until more is known, additional precautions for all people with advanced HIV or poorly controlled HIV, should be employed.

At present there is no evidence that the risk of infection or complications of COVID-19 is different among people living with HIV who are clinically and immunologically stable on antiretroviral treatment when compared with the general population. Some people living with HIV may have known risk factors for COVID-19 complications, such as diabetes, hypertension and other noncommunicable diseases and as such may have increased risk of COVID-19 unrelated to HIV. We know that during the SARS and MERS outbreaks there were only a few case reports of mild disease among people living with HIV.

To date, there is a case report of a person living with HIV who had COVID-19 and recovered and a small study on risk factors and antiretrovirals used among people living with HIV with COVID-19 from China. This study reported similar rates of COVID-19 disease as compared to the entire population and increased risk with older age, but not with low CD4, high viral load level or antiretroviral regimen. Current clinical data suggest the main mortality risk factors are linked to older age and other comorbidities including cardiovascular disease, diabetes, chronic respiratory disease, and hypertension. Some very healthy people have also developed severe disease from the coronavirus infection.

PLHIV are advised to take the same precautions as the general population:

- wash hands often
- cough etiquette
- physical distancing
- seek medical care if symptomatic
- self-isolation if in contact with someone with COVID-19 and
- other actions per the government response

People living with HIV who are taking antiretroviral drugs should ensure that they have at least 30 days and up to 6-month supply of medicines and ensure that their vaccinations are up to date (influenza and pneumococcal vaccines). Adequate supplies of medicines to treat co-infections and comorbidities and addiction should also be ensured.

For the full article and more information from the World Health Organisation, please go to www.who.int



DENTAL ISSUES & BLEEDING DISORDERS

Do they mix?

I don't mind going to the dentist. I have no fillings. I have been lucky. However, last year I needed a tooth removed. I cracked a tooth from grinding my teeth at night. Ugh! I had the crack filled, but it became infected.

My dentist knew about my haemophilia and was happy for me to contact the Haemophilia Treatment Centre. They advised me to have the tooth removed at The Alfred. I had a course of tranexamic acid mouth wash and tablets, with no bleeding.

I have another cracked tooth next to the one that was removed. Therefore, I have the issue that if I didn't replace the tooth, I would risk losing the other tooth. Because it is cracked, I also can't have a plate put on the cracked tooth.

Sooooooo..... the discussion about an implant began. This could not be done at The Alfred, as it is an elective procedure. Mmmmmmm. What to do.... It took some organising, but liaising between the HTC, a local haematologist in Geelong, and my very understanding dentist, it all came together.

I had the implant procedure done at a private hospital where the anaesthetist organised a DDAVP infusion to increase my clotting. I went home with TIA mouth wash. It is a procedure that can be done in the chair, but I was not comfortable with that and the potential bleeding issues could not be managed.

Everything went well. Four months later I had the crown put on the implant. No bleeding. I believe this is because all precautions were taken, and everyone worked together. It took some extra time and precautions than for the average person, but the peace of mind and absence of bleeding issues was all worth it.

Sharron Inglis
HFV Member

REMEMBER:

- Get regular dental check ups to minimise future dental procedures
- Always check with your treatment centre before undergoing dental procedures
- Make sure you allow plenty of time for organising the appropriate level of care needed for your required procedure

Looking after your VEINS

Home treatment and prophylaxis have become a way of life for people with haemophilia. It is very important to look after veins as you will need to use them for a long time.

While giving factor may be challenging, you or your child's caregivers are the best people to administer factor replacement therapy using veins once you know how to do it.



muscles tighten, clamping off veins that run through them. This makes all the blood that flows into the arm return through surface veins. This causes veins to become larger and stronger, making them easier to find and use.

Remember, it's like any other exercise. It only works if you do it regularly,

WHAT ARE VEINS?

Veins carry blood back to the heart and lungs from around the body. They have thinner walls than arteries; they lie closer to the surface and do not pulsate. The veins closest to the skin's surface are used to get blood during a blood test or to put medication into the body.

Having good veins to give factor through is not just about good luck. Learning how to do this properly and then looking after veins is important and requires work.

Have you ever noticed how body builders and brick layers usually have big, strong veins? This is because of the upper arm exercises and work they do. You can make veins bigger in your arms by doing some simple exercises.

EXERCISES FOR VEINS

1. Squeeze a sponge ball in your hand. Start with ten squeezes daily and build up to 50 squeezes per hand daily. This exercise helps to develop the supporting muscles.
2. Place a tourniquet around your upper arm. It should be tight enough so that your veins stand out in a few minutes, but not so tight that you can't feel a pulse at the inside elbow. Squeeze your fingers in and out with/without a sponge ball until your arm gets tired. Loosen the tourniquet and rest a little, then repeat this exercise again. If you do this frequently, at least twice a day, it will improve your veins.

HOW DO THESE EXERCISES IMPROVE YOUR VEINS?

When you do these exercises, your

and it will certainly help with your infusions.

VEIN ROTATION

Medicines that are given through veins can irritate the walls of the veins. Changing which veins you use can help decrease irritation and scarring.

When you put a needle in your skin, it leaves a small hole that needs to heal. The same is true with your veins. You can keep your veins in good shape if you let them heal before you use them again. If you don't let your veins heal, you may be at risk of collapsed veins or infections.

Rotating your vein is often recommended, where you let one spot heal while you use another. A vein usually takes a couple of days to

heal. It is also useful to have a back-up vein that is used to being injected in case you have issues with your regular vein.

TIPS FOR TREATMENT

WHAT CAN YOU DO TO MAKE THINGS GO MORE SMOOTHLY WHEN YOU NEED TREATMENT?

The following are tips and tricks which may help you:

- Clean – Always wash your hands before you start and have a clean area to make up and give your factor.
- Drink plenty of fluids – make sure you have enough to drink before you try to give your factor so that your veins are plump and bouncy.
- Keep warm – if you are cold, your veins will shrink and will be much more difficult to find. This is sometimes a problem in winter so it helps to put on a jacket to keep warm. Have a warm shower or bath. A warm breakfast or cup of hot chocolate/milo will warm you from the inside. If you are still having problems then a heat pack over the vein you are using is a great way to warm you up and help make it easier to find your veins.
- Environment – makes sure there is good lighting where you are sitting and you are comfortable and relaxed. If you are stressed or scared then your veins know this and make it more difficult to find them. Sit somewhere comfortable and if you need to be distracted, turn on music or the TV. Take a few deep breaths before you start if you need to calm yourself.



- Exercise – being fit and healthy means you will have better veins. A healthy weight range also makes it easier to find and feel your veins. Just before you have your factor, doing a quick round of exercise such as running on the spot or star jumps will help get your blood pumping and make finding your veins easier.
- It is better to use a plump bouncy vein that you can feel than a vein you can only see. If a vein is plump and bouncy it will be easier to access than a vein that is visible but flat. Take your time to feel and get to know your veins and the direction they are running.
- Position – make sure you have your arm below the level of your heart. Dangling your arm over the edge of the bed/chair before you access your veins will allow gravity to increase blood flow to the area and the vein. After applying the tourniquet squeeze a rubber ball or make a fist or flap your arms up and down to help increase blood flow.
- Use distraction for small children – TV, DVDs, iPad, toys, bubbles, Buzzy Bee, another person. Anything your child likes is helpful.
- Pain relief – using anaesthetic ‘numbing’ creams. Remember to remove and clean the area well. Finding the veins is easier if the cream has been removed for around 10 mins before trying to use the vein.
- Avoid pressure on the needle insertion site during an infusion or when taking the needle out. Remember to release the tourniquet before you start infusing your factor.
- Apply pressure after the needle is removed to make sure the bleeding has stopped. If you do not apply adequate pressure for long enough then you may get a bruise over the vein making it difficult to feel when you next need to use it. Using a pressure band aid will help prevent bruising. Looking after your vein makes it much easier to find the next time you need treatment.
- Rotate vein sites as needed – you may not need to do this but if you are having problems with the vein, it is always good to have an alternative to use.
- If you need a blood test – ask the health professional you are seeing if you can access your vein yourself or if they could use a different vein to your regular vein.
- Ask for help – sometimes you will have problems despite your best efforts. Remember, it is ok to ask for help if you are having problems.

HELP

For more information about looking after your veins, talk to the haemophilia nurse at your Haemophilia Treatment Centre.

ROBYN SHOEMARK AND HELEN STAROSTA

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COVID-19: UPDATE FROM HFA

YOUR HTC'S

It's an important time for people with a bleeding disorder and family members and carers to follow advice provided by your HTC and plan well ahead when this is possible.

HFA greatly appreciates the current work of our health service providers in such difficult circumstances. We recognise the enormous pressure they experience from increased workloads and uncertainty, and the personal sacrifices they are making. We are grateful for the steps HTCs are taking to meet the needs of people with bleeding disorders.

YOUR TREATMENTS

We are in regular contact with HTCs, the Australian Haemophilia Centre Directors' Organisation, the National Blood Authority, Lifeblood (formerly the Australian Red Cross Blood Service) and suppliers of both recombinant and plasma derived clotting factor products.

Advice from HTCs is that it is very important to follow your usual management plan to both prevent bleeds and manage bleeds promptly to minimise complications. If you are prescribed regular prophylaxis (preventative doses) of factor concentrates for home treatment during this time it is imperative that you adhere to your prescribed treatment regimen and don't miss any doses.

If you are on prophylaxis, preventing serious bleeds that may require hospital contact or admission is of utmost importance in the current climate. Treating injuries early is also key to avoid a more significant bleed that may have serious consequences.

If you are having a bleed do not delay calling the HTC for advice, particularly if you don't treat at home.

Older people and people who are vulnerable due to a compromised or lowered immune system or existing respiratory/lung conditions should minimise trips outside the house, except to seek fresh air briefly and to obtain necessities.

TREATMENT SUPPLIES AND HOME DELIVERY

Don't forget to be proactive with your prescription needs because if you leave it until the last minute you may not be able to find a health provider at your HTC to assist.

Don't forget to place your orders within the appropriate timeframes. Follow any changes advised by your HTC team.

We are advised by the National Blood Authority (NBA) that there are adequate supplies of both plasma derived and recombinant clotting factor and other blood product treatments at this time. There is no need to stockpile your clotting factor.

The NBA advises that suppliers have taken steps to ensure appropriate social distancing at home deliveries. Signatures may not be required so that you and the driver maintain necessary social distance. As always, the authorised receiver must be available to take delivery and deliveries are to be made within the agreed delivery window.

Don't forget to update your delivery address if your stocks are usually delivered to your work and you are now at home.

If you are in quarantine, make sure your HTC and home delivery suppliers know so they can make appropriate arrangements for you.

Make sure your haemophilia team is advised if you are admitted to hospital for COVID-19 to ensure ongoing treatment of your bleeding disorder, and particularly if you are treated with Hemlibra which requires very specialised management.

For additional information about treatment product supply see the NBA website <https://www.blood.gov.au/response-novel-coronavirus-2>

QUESTIONS?

If you have general health or coronavirus concerns you are advised to contact your General Practitioner for advice. Do not change medications you are currently taking or begin new medications

without consulting with your doctor.

If you have concerns about treatment for your bleeding disorder or your treatment product contact your HTC team in your usual way. Do not attend the HTC unless you have been instructed to do so. If you are having a bleed and require advice do not delay calling the HTC for assistance.

HOW ARE YOU FEELING?

It is understandable that people might feel worried, vulnerable and stressed.

For those at home alone or living in their "bubble" as they are required to do, it can be very lonely. When new issues arise it might be confusing and complex to decide the best action to take.

Self isolation, quarantine requirements and social distancing impact all of us, whether it is separating us from the loved ones we would usually see regularly for company and support, or that we are working from home and being thrown together with the whole family when we are not used to that. This can be very tough and it needs adjustment and understanding.

Further, work commitments can take many people away from the loved ones they want to care for and protect at home when they are also needed in their workplace to perform an essential service to keep the rest of us safe and well.

If you need help with the way you are feeling, there are organisations that can help you. You can contact the social worker, counsellor or psychologist at your HTC, or speak to your General Practitioner.

You can also receive help by contacting the following organisations:

- Lifeline – 13 11 14
- Beyond Blue – 1300 22 4636

Sharon Caris
Executive Director - HFA
www.haemophilia.org.au

Haemophilia Foundation Victoria

ONLINE

TRIVIA NIGHT

JOIN US FOR A FUN COMMUNITY &
FAMILY FRIENDLY NIGHT IN

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BUT LOTS OF FUN!
7PM - 8PM
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BUILDING INDEPENDENCE

PARENTS

Since the day your child was born you have loved and provided for your child, as any good parent would. But as a parent of a child or children with a bleeding disorder, you've had to become a nurse and teacher too. You've had to care for your child's medical needs and have taught yourself, your child, your family, as well as your child's teachers and other caregivers, about your child's health, educational, and emotional needs.

You've been working toward the day your child becomes independent—when your son or daughter can take care of him- or herself. You've tried to teach your child to advocate for his or her needs. You've looked forward to your child's pursuit of a higher education, getting a job, and starting a family.

So why is it so hard to let go?

Most likely you wonder if you've done enough. Will your children remember everything you taught them? Can they speak up for themselves even when under stress? It's difficult to watch your child struggle or make mistakes, and it's especially hard when a mistake can be life threatening. However, providing your son or daughter with the tools to live independently will not only benefit your child but also you and your relationships with your spouse and other children.

How Building Your Child's Independence Benefits Your Young Adult Promotes Self-Esteem and Confidence

Being able to speak knowledgeably

about his or her bleeding disorder, feeling secure in treating and caring for his or her disorder, and being able to speak for him- or herself in emergency situations promotes a sense of mastery in a child's life.

Creates Opportunity

When your child can care for him- or herself, the door will open to many other opportunities. Your child can go away to school, visit family and friends, and continue to create relationships outside of the immediate family and home.

Encourages Becoming a Mentor or Role Model

Your son or daughter can be a mentor for other children and families who are struggling with self-care. By sharing some of the challenges he or she has faced and the strategies for overcoming these obstacles, your child may be able to help others looking to start their transition towards independence.

How Building Your Child's Independence Benefits You

A Job Well Done. When your child can care for him- or herself and speak on his or her own behalf, you'll know it's because of your patience and guidance. Raising a child is hard work, but when you see your child making good decisions about his or her health and well-being, you can pat yourself on the back for a job well done.

Relax and Focus on Yourself

Most of your energy and time has gone to supporting your children. Trips to the Haemophilia Treatment Center (HTC) or emergency room and worrying about your child's physical, emotional, or academic needs have occupied much of your life. Your kids are grown or nearly

grown, and it's time for you to focus on you. They're finding their own way in life and developing their own independence. It's okay for you to try a new hobby—explore a new interest, take a class.

Create a New Relationship With Your Young Adult

Your now-young adult should be taking on the majority, if not all, of his or her medical care. That means you'll begin to see your child in a whole new way and vice versa. This is an opportunity to start a new conversation and explore a new relationship with your child. As your son or daughter becomes self-assured, confident, and independent, he or she will begin to really appreciate all the work, time, and energy you've put into raising an independent person.

What Parents Can Do to Support Their Child's Journey to Independence

Embrace your new role as coach, counselor, and confidant, rather than primary caretaker. Recognize the steps you have been taking all along to promote your child's growth and independence. Consider your child's perspective. Be prepared for setbacks. Your child may not make the same choices that you would make. Allowing independence means giving them some room to make mistakes, learn and grow.

Remember:

We learn from our mistakes.

It's better to make them in a safe, supportive environment.

Don't give up. Work through it.

Provide encouragement.

Focus on the effort rather than the outcome.

BUILDING INDEPENDENCE

YOUNG ADULTS

Since the day you were born your parents have been your safety net. They've made sure medical and school forms were filled out, appointments were made, and lunches were packed. You never had to worry about your factor expiration date or if your teachers and coaches understood your bleeding disorder. Most importantly, if you had a bleed, mom and dad were there to comfort you, start treatment, or call the doctor.

By now you're thinking about or planning for your future. You may want to attend school away from home, travel, or start a job. You can't pack mom and dad in the luggage and take them with you. You can't rely on them to continue to oversee your treatment and daily care.

Managing and treating your bleeding disorder yourself is a giant step towards independence.

Taking steps toward independence is a natural part of maturing. It may be a little daunting not knowing what to expect from the additional responsibilities that come along with gaining independence, but think about how you learned to ride a bike or to swim. Someone taught you before you were allowed to go it alone.

Taking control of your bleeding disorder is not much different. Most likely, your parents have been teaching you the steps and involving you in your care from the beginning. Your parents will continue to support you. For you to continue to move

forward, however, they must move to the sidelines and become your cheerleaders. Ultimately, you must become the manager of your life and the primary caretaker of your bleeding disorder.

How Building Independence Benefits You:

Makes You Feel Good About Yourself

Mastering a task produces a tremendous feeling of success—whether it's learning chess or learning to self-infuse. Knowing you'll react and respond appropriately in emergencies, advocate for your own needs with friends and medical personnel, and speak knowledgeably about your bleeding disorder strengthens your confidence. The result: greater self-esteem not only regarding your bleeding disorder but also other areas of your life.

Opens the Door to New Experiences

Being an expert on your bleeding disorder paves the way for new opportunities. Knowing how to advocate for yourself, manage your bleeding disorder, and keep safe allows for new possibilities and experiences, such as travel, college, jobs, or living on your own.

Improves Your Social Life

You don't want mom and dad to be your roommates at college or to take them on a date with you, do you? Taking control of your care means you can participate in activities without your parents' texting, calling, or coming with you to make sure you're safe and able to treat a bleed on your own.

Taking Steps to Independence

Your parents may have a difficult time as you transition to complete independence. It's hard for them

to imagine not being your primary caregiver. They may not fully believe that you know how to care for your bleeding disorder. They may fear you'll make mistakes and believe that they know more than you about your bleeding disorder and your body. By taking steady steps toward independence, you'll show them you are ready to take care of yourself and build their confidence in you.

Here are some steps to bolster your independence:

- Take on additional responsibilities outside of your medical care, such as household chores. This will show your parents you're serious about gaining more responsibility.
- Learn how to self-infuse, order factor, and begin making your own medical appointments.
- Learning all that's involved in your care lets your parents see that you can handle additional responsibility and that you don't expect them to care for you forever.
- Make good choices regarding academics, sports, and your health.
- Discuss the pros and cons of your options with your parents to show you take the decision-making process seriously.
- Work with your parents and your Haemophilia Treatment Centre (HTC) on a plan to transition to taking on more responsibility for your own care.
- Don't get discouraged when you make a mistake. Talk it over with your parents and the staff at your HTC.
- Recognising your mistakes and learning how to identify, correct, and keep from repeating them is all part of becoming independent.

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National Hemophilia Foundation
www.hemophilia.org*

TOP TIPS

FOR LOOKING AFTER YOUR MENTAL HEALTH WHILE SELF-ISOLATING

There are a number of ways to support your mental health during periods of self-isolation or quarantine.

- Remind yourself that this is a temporary period of isolation to slow the spread of the virus.
- Remember that your effort is helping others in the community avoid contracting the virus.
- Stay connected with friends, family and colleagues via email, social media, video conferencing or telephone.
- Connect with others via the Beyond Blue forums thread: Coping during the coronavirus outbreak .
- Engage in healthy activities that you enjoy and find relaxing.
- Keep regular sleep routines and eat healthy foods.
- Try to maintain physical activity.
- Establish routines as best as possible and try to view this period as a new experience that can bring health benefits.
- For those working from home, try to maintain a healthy balance by allocating specific work hours, taking regular breaks and, if possible, establishing a dedicated work space.
- Avoid news and social media if you find it distressing.

SEEK SUPPORT

It's normal to feel overwhelmed or stressed by news of the outbreak. We encourage people who have experienced mental health issues in the past to:

- activate your support network
- acknowledge feelings of distress
- seek professional support early if you're having difficulties.

For those already managing mental health issues, continue with your treatment plan and monitor for any new symptoms.

Social contact and maintaining routines can be supportive for our mental health and wellbeing. In circumstances where this is not possible, staying connected with friends and family online or by phone may assist. Beyond Blue also has a dedicated page on its forums about coping during the coronavirus outbreak .

Acknowledge feelings of distress and seek further professional support if required.

Beyond Blue has fact sheets about anxiety and offers other practical advice and resources at beyondblue.org.au .

If you need assistance please visit the dedicated Coronavirus Mental Wellbeing Support Service. Trained mental health professionals are available to talk to you 24 hours a day, 7 days a week, via phone, webchat and email.

Source: Beyond Blue



www.beyondblue.org.au
1800 512 348

“

years ago, and love living here.

Throughout his life, up until 4 or 5 years ago, John's haemophilia didn't stop him from doing a great variety of jobs, participating in sport (mainly canoeing), enjoying family life with our two children, five grandchildren, and now, one precious great granddaughter.

Mostly, treatment at the Alfred had been fairly infrequent, usually

My husband, John, is 81 and has mild haemophilia A. We retired to Ocean Grove nineteen

usually followed by coffee with most of the class, at the cafe next door.

Many musicians, of varying level of skill, mostly from towns on the Bellarine Peninsula, gather once a month or more to play together, and these evenings are full of fun.

He felt quite honoured a couple of weeks ago, when he was asked to join the music group leading our church service, to play his ukulele for a couple of songs. One of them was what you might call quite rollicking, and had the whole congregation enjoying a great time singing.

After he had been learning and playing for about 18 months, John



MUSIC & HAND CRAFTING INSTRUMENTS

Passion & Pleasure

as a result of the occasional fall or knock, interspersed though, with a number of ankle bleeds. Eventually his ankles have succumbed to fairly debilitating arthritis, and now he finds walking and standing difficult and painful.

John has always loved music, and enjoys listening to many different genres, mostly favouring music and artists from the sixties and seventies. In his younger days he played bass guitar in a band. About four years ago we went on a cruise, and ukulele lessons were offered. John was immediately interested, and went along.

This was the start of a whole new interest. When we returned home from the cruise, he found a local ukulele class, and enrolled in the beginners section. Since then, he has graduated to the intermediate class, and thoroughly enjoys his time there each Thursday morning,

decided he would like to also become involved in building ukuleles, and joined the local woodworking club. He has since completed a bass and a soprano ukulele. He is currently working on a tenor. It has revived his interest in french polishing, a skill that two of his uncles taught him as a young teenager.

I am sitting in our office/music room writing this, smiling as I look at the eight, yes eight, ukuleles hanging on the wall.

The last few years have had many challenges and changes for us, brought about by joining the seriously old age bracket, but I think, for both of us, these would have been much more difficult to deal with, had it not been for his great new interest in ukuleles.

Joan Bates
HFV Member



”

A creative way to become **MINDFUL**

Holistic? Mindfulness? But my children do not like to do mindfulness activities!

According to the Cambridge Academic Content Dictionary, “holistic” in medical terms refers to looking at a person as a whole, considering physical, emotional, social and spiritual well-being instead of focusing on injury or disease itself.

An overwhelming number of evidences shows that being mindful helps us to be more aware, non-judgemental, and allows us to create a space where we empower ourselves to choose healthy thoughts and reactions to situations. Some examples of mindfulness activities are – to focus on your breathing, paying attentions to surroundings, listening to sounds and participating in guided meditations.

Adults need to have disciplines and children need a facilitator to achieve with persistent training, so they can master this practice. My personal experiences tell me children are generally quite mindful and exceptionally good at focusing on ‘here and now’.

I want to share a mindful practice where the whole family can participate and enjoy, without children knowing that they are doing ‘mindful’ activities (some children don’t like to do these activities as soon as they hear a word ‘mindfulness’). Adults might be surprised to rediscover how very mindful children are, and in fact, maybe, we are the ones who need a lesson on mindfulness from children!

1. Bring a large bag and go for a walk with your family. Pay attention to the scent and sound around you. Notice if you can see anything the same and/or different from usual. (We mostly take the same route, but I tell the children there is always something new/different we can find if you pay attention. Children never

fail to find something new!)

2. Collect what you feel like from your walk. They can be anything from gum-nuts to fallen leaves, acorns, pinecones, or anything you feel like. We found it was better to collect many. Just make sure you remember hygiene practice and never pick mushrooms or unfamiliar insects. Do not forget to wash hands after.

3. Whilst walking, notice how the sky changes its colours, naming what you can see. Feel the air and wind.

4. When you get home, take a moment to look at objects you have collected. Play with them for a while, paying attentions to textures, colours, shapes. Do they all look the same? How does it feel to hold them? Can you make any sounds with them?

5. Start arranging them in a way that you like. There is no right or wrong answer. This is where your creative mind can kick in. Let your hands guide your activity, not your mind.

6. Look at what you have created. Did you enjoy the process? Did you have any conversations with yourself and your family when you are making them? Have you noticed any self-talk you did not notice before? Would you like to do it again?

7. Keep your creations if you like. Have you noticed a change or non-change within your feelings, sensations, and thoughts before and after the activities?



We did this as a family and the children loved it! We arranged and rearranged objects and continued making a variety of patterns and creations. We left them in our garden for a few days and noticed some birds visiting us to pick things off the ground.



This type of activity engages you to be here and now, as there are prompts to pay attention to the present moment. Touching and experiencing natural resources help you to bring your focus on physical sensations. You may even notice how your mind is centred while arranging the objects. Try and see how you feel. Remember, there is no right or wrong in here!

Healthy lifestyle and regular treatments are not a golden ticket to cure severe haemophilia for my boys. Some parents might go into a self-blame path. Sometimes we are caught up in a thought of fear and worries generated from the past that we cannot change, or the future which has not come yet. Some of us have gone through a trauma that an automatic reaction from a trigger leaves us feeling overwhelmed. With confirmation, there is no magic cure that instantly fixes a situation. However, I can say this with confidence, NOTHING stops us from having a happy life. Ultimately, we all have a choice over our mind, a power to create, abundant ideas and hidden unique talents. Our special uniqueness can only come to light when our fears and worries stop taking over ourselves. It would be such a shame, to continue feeding our energy and power into fear, worries, self-blame to bury all those good aspects of ourselves. So, let us just start treating us better. Be our best friends and start being kind to ourselves. This first step will eventually lead to a better management of bleeding disorders.

Nao Ikoma - HFV Member
*Holistic Integrated Creative Arts
Therapist & Reiki Practitioner*

From my bunker

As a senior citizen and long term participant in public health programs, I have been very encouraged by our community response to lockdown restrictions which protect our health delivery systems and the vulnerable and elderly in our population.

It has been a very challenging time for many people and I hope that as members of the bleeding disorders community, you have been able to find personal and professional support.

I was fortunate to arrive home in Australia, deftly negotiating border closures and airline cancellations, to mandatory home rather than hotel room self-isolation at the end of March.

Since that time I have mastered Zoom and other forms of teleconferencing and kept busy with my roles at the National Blood Authority and with the Asia Pacific Haemophilia Working Group. Our technologies are expanding to allow the core work to continue. And it's lucky that the other participants can not see my slippers, I have never worn them so much.

Keeping up with friends and family, now extending to limited personal visits and hugs at a distance has been crucial. It's very hard to imagine going through a pandemic without online support.

I do hope that all of you are well and as you care for each other are in turn being cared for.

My very best wishes and thanks to all at HFV and at our state haemophilia centres.

I hope to see all of you in person or on screen soon as we enter a reset world together.

Warmest regards
Alison Street - HFV Patron

COVID and me...

Who would have thought a pandemic could impact on us so profoundly. A gift of time for gratitude and reflection but with it comes the fear of what next.

My work has changed completely. I am supporting vulnerable people at risk of abuse in isolation or increase risk of harm online. With HFV, I am worried about the isolation of our members, will they know we still care and how to still connect when physically isolated. On the home front I miss family and mates to share a meal or a drink. But loving the extra time in my day not commuting, extra coins in my pocket from less café lattes which is all going towards more online shopping than ever before. I feel I am doing more self-care than ever before. I know I was always busy but now I cannot remember what I was doing in that busyness. As Alice would say in Wonderland...curiouser, curiouser.

Leonie Demos

SHARING OUR EXPERIENCES OF THE COVID-19 LOCKDOWN



Covid 19 and taking the time to slow down

At first, it felt a bit daunting to self isolate but our family embraced it the best we could. From home made meals including slow cooking recipes (because now we have time) to regular pushbike rides to a daily yoga practice, we took the time to slow down and enjoy each others company. We knew it wasn't going to be a permanent change so we thought we might as well make the most of it. As life is slowly going back to a new normal, we will not forget what we learnt: it is OK to slow down and do absolutely nothing from time to time.

Ben, Claire and Louis



During the lockdown I have been keeping myself entertained with video games, and binge watching tv shows. I've also done a bit of online shopping, buying new movies and games to play, as well as some diamond art paintings that I have been working on during the lockdown.

Cara Gannon



LIFE IN LOCKDOWN

ALEX & JANE - ALFRED HOSPITAL HTC TEAM

Most people in the community are living their lives somewhat differently.

It is amazing that although the pandemic is having a devastating effect in many ways many people are managing to keep a positive approach. However, all of us at times are facing complications; changes that we are having to adapt to, situations that we would rather not have, and interruptions to major lifecycle events. The World Federation of Hemophilia held an interesting webinar on the 4th of May "Stepping up and not stepping out". It provided some interesting insights and facts about haemophilia and COVID 19.

- At this stage it is understood that people with haemophilia are not at increased risk for having COVID-19.
- There may be some risk factors for the severity of the disease.
- It is highly unlikely that COVID-19 can be transmitted through plasma products, but this is being closely monitored.
- Looking after someone who has COVID -19 with a bleeding disorder is complicated.

PSYCHOLOGICAL ADVICE

Some of the ideas suggested are:

- Have a positive attitude.
- Reach out to others in ways that you can.
- Be careful not to do too much social media.
- Find ways to support yourself through boredom
- Take it one day at a time.
- Remember to celebrate the good things, and not always focus on the bad things.
- Try to be aware of the difference between helpful emotions and unhealthy emotions.
- "It's not the stress that kills us, it is our reaction to it" Hans Selye quoted by Richa Mohan from India.
- When you recognize the unhelpful emotions then you can use some different strategies to manage these emotions, try and shift your thinking, find something else to think about, ask for help from someone in your circle, or a professional. (The Social worker at the HTC is a good choice, but equally your GP can refer you for counselling, and the GP and the counsellor should be able to do telehealth if needed.)
- Keep a positive mindset. We know that this reduces the negative impact of the situation.

HOW CAN YOU KEEP A POSITIVE MINDSET, OR MANAGE YOUR REACTIONS TO THE STRESS AROUND YOU?

Everyone has some good stress management techniques, if yours don't seem to be working at the moment then there are a few things you can try

- Talk to your friends, family or colleagues
- Have a go at changing your attitude with how you talk to yourself (you can influence your own positivity a great deal).
- Recognize all the different feelings that you might be having, it's ok to feel whatever you feel, it's just what you do about your feelings that can cause you problems. If you don't let the feelings out, they can stay with you and cause you trouble.
- Try to name the different feelings. This is really powerful. Often once you name it you can address it for yourself. If it's not so straightforward, then try and understand them and give yourself permission to have these feelings. It might be a puzzle that takes some time to solve.
- There is no right or wrong with feelings, they are your own reaction to your situation.
- What ways can you find to express these feelings that don't damage yourself or others? Scrunching paper, throwing soft objects somewhere safe, writing, art, or craft, finding someone to talk to, for a start.

Link to WFH presentation about Covid 19 is available on the WFH website if you are interested.

<https://elearning.wfh.org/resource/stepping-up-and-not-stepping-out-a-nursing-and-psychosocial-perspective-to-covid-19/>

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

Useful links for Covid-19 support & information

- Australian Commonwealth Government – <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert>
- Beyond Blue – <https://coronavirus.beyondblue.org.au/>
- Black Dog Institute - <https://blackdoginstitute.org.au/coronavirus-anxiety-resources> and they are running webinars around coronavirus and mental health
- Emerging Minds have resources for discussing COVID-19 with children - <https://emergingminds.com.au/resources/communicating-with-your-child-about-covid-19/>
- Haemophilia Foundation Australia – <https://www.haemophilia.org.au/publications/news/covid-19-update>
- Reach Out - <https://au.reachout.com/articles/10-ways-to-take-care-of-yourself-during-coronavirus>
- Victorian Government - <https://www.dhhs.vic.gov.au/coronavirus-covid-19-daily-update>
- Ten per cent Happier have a fleet of free meditations and podcasts around coronavirus - <https://www.tenpercent.com/coronavirussanityguide>
- World Federation of Haemophilia - <https://www.wfh.org/en/covid-19-communications>
- World Health Organisation - <https://www.who.int/publications-detail/WHO-2019-nCoV-Mental-Health-2020.1>

Alex Coombs & Jane Portnoy

Social Workers, Haemophilia &

Other Inherited Disorders Team Alfred Health



HFA Getting Older project update COMING SOON!

Look out for the HFA Getting Older needs assessment report.

There will be

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

These will be available online on the HFA website www.haemophilia.org.au and in print.

And keep an eye on the HFA website www.haemophilia.org.au for the upcoming Getting Older Info Hub.

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



**Let's talk
about
getting older**



CONNECTING THE GLOBAL BLEEDING DISORDERS COMMUNITY

The World Federation of Hemophilia (WFH) is committed to bringing the bleeding disorders community together in the name of Treatment for All. This commitment is especially important during the COVID-19 crisis. In June 2020, we will be bringing our community together virtually.

The WFH is pleased to announce the launch of the WFH Virtual Summit: Connecting the Global Bleeding Disorders Community. This series of live and recorded sessions will take place from Monday June 15 to Friday June 19, 2020 and will allow you to connect with the community and increase your knowledge from the comfort of your home. The approximate time slot will be 9 a.m. to 1 p.m. Eastern Daylight Time (EDT) (1 p.m. to 5 p.m. GMT-4). More details to follow. News regarding pre-Virtual Summit sessions—which will take place on Sunday, June 14—will also be announced soon.

The WFH is pleased to offer this inaugural WFH Virtual Summit free of charge to the entire bleeding disorders community. Please register here to receive more information about this important event.

The WFH 2020 Virtual Summit program features many important events: plenaries, medical and multidisciplinary sessions, an e-poster session and free paper presentations, and the WFH State-of-the-art book *The WFH Virtual Summit* scientific program will provide an innovative and comprehensive overview of the latest developments in our field, current patient healthcare issues and the challenges ahead in the management and treatment for people with hemophilia, von Willebrand disease and other rare factor deficiencies worldwide.

Our program will include the following topics:

- Redefining prophylaxis in the modern era
- Inhibitors-think differently
- Gene therapy
- Substitution therapy
- Women and girls with hemophilia
- VWD
- Women ageing gracefully
- Is there a gain to pain?
- Mental health and quality of life
- Late-breaking sessions
- WFH workshops

DON'T MISS THIS OPPORTUNITY!

FREE to the bleeding disorders community
www.wfh.org/virtual-summit/home

Many sessions will be recorded and made available (as the live session times may prove prohibitive for Australians to attend) so register your interest now.

A TALE OF TWO SOCIAL WORKERS

Jane Portnoy on Shaping the Future

This time last year I was lucky to be planning for a trip to a conference Shaping the Future, The International Social Work Conference on Health and Mental Health in York, England. Who knows when this sort of conference will be possible again?

I am grateful that I had this opportunity and HFV's support helped me to attend.

At the conference opening a wonderful social worker was remembered, Helen Rehr, from New York, in her words "I can't think of any serious health problem that doesn't have significant psychosocial implications." Another eminent social worker David Epstein added that equally he "couldn't think of any serious psychosocial problem that doesn't have significant health implications."

The impact of health on your psychological and social wellness and vice versa is probably better understood by people with bleeding disorders.

This conference was a wonderful opportunity for me to explore new ideas in my field and hear the leaders talk about their projects and passions, and be a part of the development of our knowledge and practice.

- Incorporating the service users into practice and service design
- Ideas of decolonization
- Global collaboration
- Compassion
- Sibling grief
- How we compare our work to the work of our colleagues in order to understand and improve
- Research in health social work

I presented a talk and a poster on Transition to the Adult hospital for young people with haemophilia and the poster was called "A Tale of Two Social Workers". Giving a presentation like this was outside of my usual comfort zone but worth all the worry and effort. The contacts I have made with social workers all around the world, and the discussions that followed continue to enhance my understanding of barriers in transition and ways to improve our service.

I look forward to continuing to develop our service through collaboration, research, dialogue and reflection.

Thanks to HFV for the support.

Jane Portnoy
Haemophilia Social Worker
Alfred Health

Alfred contingent, Alice Brown,
Jane Portnoy & Bronwyn McFadyen





Keeping children safe online during the COVID-19 pandemic

The global impact of COVID-19 means young people will be spending more time at home — and more time online. There are lots of great ways children can use connected devices to learn and play, but there are also risks.

As parents and carers, you have the best opportunity to support and guide your children to avoid online risks and have safer experiences. Governments and industry also have a role to play in making sure the online world is a safe place to be.

In these uncertain times, children may feel isolated or anxious, and might see family members disturbed by the COVID-19 impacts. Away from school, children have less access to their usual support systems including friends, teachers and counsellors. If possible, it could be useful to reach out to your child's regular support people to check if they can provide online or telephone support.

This guide covers some of the key online safety issues for young people and includes a range of practical tips and advice on what to do if things go wrong. It covers common online safety issues like managing time online, using parent controls and setting and responding to issues like cyberbullying, inappropriate content, sending nudes and contact from strangers.

For more information, please explore the [eSafety website](#).

Please note: these materials have been created by Australia's eSafety Commissioner for international use. The material is therefore general in nature. It is made available on the understanding that the eSafety Commissioner is not engaged in rendering professional advice.

Here are 10 top tips to help protect your children online.

1

Build an open trusting relationship around technology — keep communication open and supportive so your child knows they can come to you if something goes wrong or does not feel right online.

2

Co-view and co-play with your child online. This will help you better understand what they are doing and why they enjoy an app, game or website, as well as providing a great opportunity to start conversations about online safety.

3

Build good habits and help your child to develop digital intelligence and social and emotional skills — such as respect, empathy, critical thinking, responsible behaviour and resilience — and practice being good online citizens.

4

Empower your child — wherever possible, help them make wise decisions for themselves, rather than telling them what to do. Try to provide them with strategies for dealing with negative online experiences that will build their confidence and resilience.

5

Use devices in open areas of the home — this can help you manage and be aware of who your child interacts with online through phones, tablets, smart TVs, gaming consoles and other connected devices.

6

Set time limits that balance time spent in front of screens with offline activities — a [family technology plan](#) can help you to manage expectations around where and when technology use is allowed — you could even fill in an Early Years [Family Tech Agreement](#).

7

Know the apps, games and social media sites your kids are using, making sure they are age-appropriate, and learn how to limit [messaging or online chat](#) and [location-sharing](#) functions within apps or games, as these can expose your child to unwanted contact and disclose their physical location. For more advice

- [The eSafety Guide](#) includes information to help parents and carers choose safer apps and report and block unwanted contact and sexual approaches.

8

Check the [privacy settings](#) on the games and apps your child is using and make sure their profiles are turned on to the strictest privacy setting. Restrict who can contact your child or ask them to check in with you before accepting new friends.

9

Use available technologies to set up [parental controls on devices](#) that can filter harmful content, monitor your child's use and limit or block their time on connected devices or functions (e.g. cameras, in-app purchases).

10

Be alert to signs of distress and know where to go for more [advice and support](#).

- Report harmful online content to eSafety at [esafety.gov.au/report](#).
- Contact a free [parent helpline](#) or one of the other many great [online counselling and support services](#) for help. Kids, teens and young adults can contact [Kids Helpline](#) online or by phone on 1800 551 800 and the service also provides guidance for parents.

connect, support,
empower

CONNECTING from home

Events for HFV members



LADIES NIGHT IN

Join other women with bleeding disorders and carers of those with bleeding disorders.



MENS NIGHT IN

Join other men with bleeding disorders.



YOUTH NIGHT IN

Join other youth with bleeding disorders and siblings of those with bleeding disorders.



Staying connected

HFV is offering an online TRIVIA NIGHT to help keep us all connected. See page 9 for details



Fun nights in together

There will be facilitator run online activities over the next couple of months...with a focus on FUN!

All events will be advertised through our website and Facebook page once the dates have been finalised.

www.hfv.org.au

HOW TO HELP SENIORS GET ONLINE

Do you have an older friend or family member who would benefit from learning or improving their tech skills?

You can support older people to safely navigate the digital world by using the FREE Be Connected learning resources developed by eSafety.

Be their biggest advocate by demonstrating how the internet can be meaningful for them, and supporting them as they explore. If you can't show them in person, try giving them some instructions over the phone, by email or by sharing our easy steps for making video calls. Then you can talk through the other Be Connected learning resources together.

Be Connected is a good place to start

Be Connected is an Australian government initiative developed by eSafety and the Department of Social Services to increase the confidence, skills and online safety of older Australians.

<https://www.esafety.gov.au/seniors/how-help-seniors-get-online>



MEMBERSHIP RENEWALS 2020 - 2021

Your annual membership subscription for this coming financial year has been included with this edition of The Missing Factor.

We are aware that many people within our community may be financially impacted by COVID-19. Our committee certainly do not wish to 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.

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

Your support at this time is very much appreciated.

CONNECT SUPPORT EMPOWER

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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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 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.
This year we are hoping to organise a indoor soccer session - dates to be confirmed!

HAEMOPHILIA FOUNDATION VICTORIA



Social Networks

**WE ARE
STRONGER
TOGETHER!**

**facebook.com/
haemophilia-foundation-victoria**