HAEMOPHILIA FOUNDATION VICTORIA INC

SUMMER 2019

THE MISSING FACTOR

UPPER LIMB HEALTH

LOOKING AFTER CHILDREN WITH A BLEEDING DISORDER

USING CRUTCHES AFTER A BLEED

HAEMOPHILIA FOUNDATION VICTORIA INC

CONNECT · SUPPORT · EMPOWER

connect • support • empower

SUMMER 19

DIARY *DATES*

DEC
23 HFV office closure

JAN
20 HFV office re-opens

FEB
14-15 HFV Community Camp 2020

MARCH
20-22 Men's Retreat

APRIL
17 World Haemophilia Day

OCT
17 Red Masquerade Ball 2020

REGIONAL & OUTER METRO VISITS

Please contact the HFV office if you would like us to visit your town in 2020.

Please note: Due to HFV premises moving to the NBN we will no longer be able to offer a fax option.

Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

PRESIDENT'S REPORT

Another busy year at HFV as we start counting down to the holiday break. Again, when we take time to reflect on the year, we see that HFV has delivered well beyond expectations.

Sadly, I missed the recent national conference, but I understand it was one of the best ones ever. Those that attended were inspired by the diversity of presentations and have brought back some great ideas to HFV for us to consider with the HTCs. There will be several reports in the newsletter so if you also were not able to be there make sure you take time to have a read. I know I am going to make sure I am here for the next conference as I am feeling like I missed a great event.

After the conference HFA hold their AGM. Many thanks to Sharron and Dan for attending while I enjoyed my extravagant European holiday. HFA continue to do amazing work and it is at national council that critical topics that impact on our community are discussed and the future considerations of priorities are cemented. I am grateful that the committee is so rich with talent that I can take a break and know that Victoria is so well represented.

At the conference dinner one of our members was acknowledged for her many years of devotion to HFA and HFV. Donna Field was announced as Australian Volunteer of the Year which was an amazing achievement. Donna and her beautiful family have spent the last 10 years 'painting the town red' for Red Cake Day. Donna has raised over $30,000 in that time and just as importantly has raised the awareness in her community about bleeding disorders and haemophilia. Donna thrives on challenges and has baked so many cupcakes it makes my head spin.

Donna, Grant, Emma and Adam are so well respected in their rural community and her efforts to continue to improve each year is truly inspiring. Not to mention Donna has also made this a national event with the support of the Bendigo Bank. Amazing indeed. We are so blessed to have Donna on committee with us but just to have her as part of our community. An award well deserved and we congratulate with all our heart. We enjoyed a celebratory dinner last week and it was so nice to really acknowledge a job so well done. However Donna hasn't retired. She will be warming her oven up again in 2020 so I throw the challenge out to others to join in the fun. Donna is up for helpers and always happy to support you in your own events.

While discussing the committee I must share that sadly we have lost three significant members at our AGM this year. Karen has been an important member of the committee and has really shaped the camp program in past years. Karen has always stepped up when asked and has always brought a positive attitude in her approach to all she does. Karen is taking a break but the good news is she will still be supporting the work of the camp subcommittee which is fantastic news. Sharron has also decided to step down from the Committee. Sharron has been my trusty VP for several years and she has left a huge gap. Sharron has always brought such passion and enthusiasm to the work of the committee and she will be missed. However we understand her need for some time and hope to still have Sharron involved in lots of other ways. We also say a very big thank you and goodbye to Zev. Zev has been a part of the HFV for so many years I have lost count. In recent years Zev has been the treasurer and has made so many improvements to our systems and investments there are too

many to mention. Suffice to say Zev's contribution will be benefiting HFV way beyond his time on Committee as he has left such a legacy. To all three who have decided to step back we say a heartfelt thank you for all the hard work and dedication you have each brought to enrich HFV. You will be so missed but we hope each of you will stay connected as we need your support in programs and peer support.

With such movement from the committee we now have some significant gaps to fill. Dan has stepped into the role of VP and I am looking forward to working alongside him to continue to grow the agency. Donna has also agreed to assist with some of the gaps while we look for a treasurer and also be a part of the Executive so we can continue with business. However we have gaps. We need the support of our community to step in to support the work. All of us including staff are always available to answer any questions and support if you are considering joining us. We have planned the dates for meetings for the next year so you can plan in advance. Teleconference is possible and as a general member there is plenty of space for you to just watch and no pressure to do any other roles. So give us a call and see what may be possible.

We celebrated our second walk around Albert Park to raise awareness of bleeding disorders on 20th October. A great day and so well supported we thank everyone for joining us. We are keen to grow

this every year and have discussed ways that we take advantage of the event to educate those around us in the broader community as well as achieve more fundraising. If anyone has a desire to do event management or some skills that could support this work we would love to hear from you. We know this could be a fantastic event for our community and it would be amazing to take it to another level. For those that have supported it many thanks and for bringing your extended families and loved ones. Such a joy to see so much red, lets work together to make next year even bigger.

In the national space there has been exciting news. HFA has been successful in the application for a HOT twinning with Myanmar. HFV along with the other foundations will be working closely with the HFA team to plan what's next and to do all we can to support the beautiful people in Myanmar. We share a bleeding disorder but their life is very different to ours. We will be keeping you posted on ways to support this important work and hope you will all learn a bit more along the way as I certainly have done already. We will build these new friendships and hope to bring you all along for the amazing ride to come. So stay tuned.

HFA never cease to amaze me with the extraordinary commitment to educate and produce such quality material to support our community. The new Gene Therapy resource has been launched and is included in this edition of the magazine. It is a product of much collaboration and hard work. Please take time to read and share with those around you that will benefit for all the critical information. Again we thank Suzanne and the broader team for the amazing work you continue to do.

HFV hosted our annual stakeholder dinner last week. Another great success and the opportunity to thank all those around us that work so hard to support our community. Our Patron, Dr Alison Street, for her continued passionate work. So many years and still as caring as ever. To the HTC teams. Another amazing year and another year of your undying commitment present every day and we thank you for keeping our community so safe and supported. HFA again I acknowledge the important work you do and the genuine partnership approach in all we do together. To Purple Soup another successful year of working together to make some fun for those that often have challenges too hard to bear. We will see you again at camp and wait to see what mischief you may have planned. To our youth leaders and Ben, in particular, you are our future and we are encouraged by the leadership you show to your peers. Your resilience and positive attitude is contagious and we thank you all for supporting our vision to grow future leaders for years to come. Ben and I have been working on structures and some plans for future development. HFV is committed to investing in our youth and encourage all to come on board.

We might be winding back for a rest period for the holidays but not for long! So much on the horizon with our Community Camp in February. It is going to a ripper! We are having it earlier this year hoping the warmer weather will give us more opportunities to have fun with the fabulous water. If you have been thinking about camp but never taken the 'plunge'…now is the time to do it. It a spectacular venue with many saying last years was the best ever. We are even hopeful to have some people from SA and Tassie join us (if we can support them in finding the funds). Don't miss out as the following year will most likely be a new destination so please support us and be part of the fun.

Speaking of fun it is so exciting to announce the next ball is coming! A Masquerade theme it will be on Saturday 17th October 2020. As the first one showed us all the fundraising sub-committee know how to throw a party. Start saving for the ticket, auction items and that new frock (or suits). It is going to be the night of the year so time to start getting excited. We need help with silent auction items and other elements for the night. Please mark it in your calendar or you will miss a fantastic night.

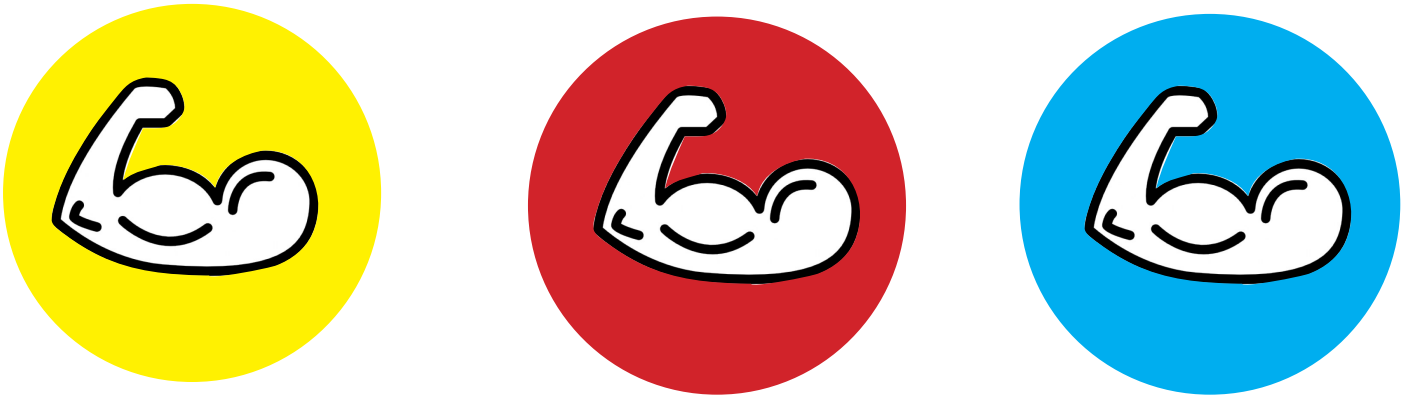
Enough from me as I feel this report has been my longest ever. However I cannot sign off for the year without acknowledging and thanking our most precious resource – our staff. To Andrea and Julia, I cannot thank you enough for all that you do. Your commitment to the work is amazing and although you fill in a time sheet we all know your hours are always way and above those we pay you for. Many thanks for another great year and for making me look good.

With everyone associated with HFV taking a break I want to wish everyone within our community a happy and safe holiday period. Regardless of your beliefs I hope you are able to spend time with your loved ones and take some time for yourselves. Life is but a fleeting moment in time and taking time to smell the roses and just 'be' seems more important than ever with the busy life we now lead. Stay well, stay happy and for 2020 stay connected. HFV needs you.

Leonie Demos
HFV President

UPPER LIMB CARE... and why it is so important

At the HFA Conference in Manly this year, there was a lot of focus on the benefits of physiotherapy. One of the sessions related to this was upper limb health.



We are all so concerned about our lower limbs and their joint damage, that we can easily forget how it can affect our upper limb health.

When we have a lower limb injury, we often end up on crutches. This can affect the health of our shoulder, elbow and wrist joints. Adding to this is the fact that upper limb joints are not as stable as lower limb joints.
The elbow has 3 different bones making up the joint. Bleeds into this area have a big impact to the movement of the elbow. Besides the general issues with regular bleeds into a joint, the long term affect is the possibility of not being able to get your hand to where you need it to be for daily activities.

"If 50% of elbow motion is lost, the cost to overall function of the upper limb can approach 80%".

Early treatment and care of the elbow joint is crucial as it is seen as one of the most important joints to care for compared to any other joint.

Immobility of the shoulder can result in balance issues and an increased risk of falls.

ULTRASOUND OF THE JOINTS

While other imaging modalities are important, ultrasound can assess the joint in real time. You can tell the sonographer or doctor where the pain is while they scan, and the effect and range of movement can be assessed at the same time.

The ultrasound can also tell if the joint has a recent bleed or if it is a chronic change. This can guide treatment and help the patient.

I found these sessions interesting because I am a sonographer. I also hadn't really thought about the importance of upper limb health specific to the challenges of people with haemophilia. I also wanted to highlight the importance of treating upper limb joint bleeds as seriously as lower limb bleeds.

Sharron Inglis
HFV Member

The concept of REST: From RICE to POLICE

Most likely, if you have attended hospital for a bleed you will have heard the mnemonic 'RICE' (Rest, Ice, Compression, Elevation). Following on the principals of sport medicine management, 'Rest' has been redefined and categorised, and with good reason.

The concept of 'Rest' is variable and non-specific. Is it 'rest' to sleep more? Or to use the limb or affected area less? Or to not use it at all?

'Protection and optimal loading' are the new buzzwords. In haemophilia management of bleeding into joints, adoption of this may be prudent. Let's break this down:

PROTECTION: We want to protect the bleeding area from more pain and from increase in bleeding (and swelling) and to prevent a re-bleed. We know that putting a muscle on stretch or in full contraction when it has blood present hurts. We know that it hurts to put a joint that is bleeding in the 'closed-pack position' where the bone ends of the joint are in the closest proximity to each other, and it similarly hurts at the ends of its range of it movement (fully bent or fully straight). So we 'rest' ie protect the joint or muscle in a position of comfort, usually around the middle of its range to reduce pain, and more bleeding.

The literature also demonstrates that we should not weight-bear on it AT ALL when it is bleeding. Research has demonstrated that weight-bearing on cartilage in joints in the presence of blood increases the incidence and rate of osteoarthritis.

OPTIMAL LOADING: Having a joint in the middle of a range for protection is optimal for decreasing pain and stopping bleeds, as described above, however the adaption of soft tissues and brain plasticity to the position they are held in is fast; you adapt quickly. You also lose muscle quickly. This is why once bleeding and pain appear to reduce we very gently start to move the joint gradually back towards gaining its full available range of movement. If this is not done range is lost and the joint becomes restricted. Once range is safely restored we work on muscle strength and normal patterns of movement.

Similarly it is vital for weight-bearing to be gradually reinstated and continually monitored; an increase in pain, further restricted movement or swelling needs to be reported as it may indicate too much too soon. Exactly when to load, and how much, will vary between people and will depend on how bad the bleed was and how the resolution of the bleed progresses. It is not the same for everyone and assessment is needed for best, personalised outcome.

Optimally loading may include a gait aid (frame, crutches, stick), a brace or support, but also may include physiotherapy techniques and graded exercise programs to restore joints, muscles, tendons and other tissues back to how they best function.

ICE: The use of ice has not changed much; there has been recent suggestion that ice may not be of benefit in bleeding management, however there has been no substantiated evidence to date that backs up that assertion. There has been evidence that ice can decrease pain. A small study on patients with haemophilia in New Zealand has been published which showed patient-reported decrease of pain and swelling with the use of ice.

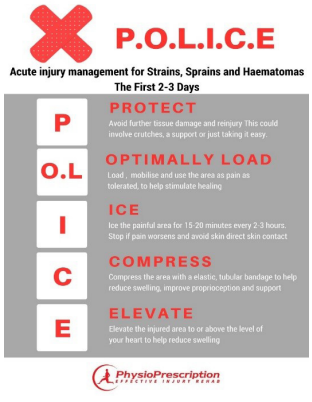
COMPRESSION: is suggested as the theory is that we are attempting to decrease swelling by changing the external pressure, which when it exceeds the internal pressure should limit the capacity for the bleed or associated swelling. In practice it has been observed that putting a well fitted compression bandage on as soon as you think you may have a bleed can decrease the severity of the bleed.

ELEVATION: uses the principals of gravity, along with the location of the body's lymph nodes to reabsorb the excess fluid. Both attempt to normalise the pressure gradients. No research has been published to date, and data would be difficult to obtain and variables affecting it large.

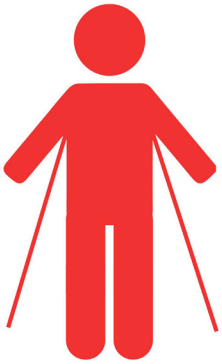
Of course once the acute stage has been managed, rehabilitation of the affected area is vital. For any stage of the bleeding and rehab process… you know where to find us physios!

Abi Polus
Musculoskeletal Physiotherapist
Bleeding Disorders
Alfred Hsopital

References
Stephensen D, Bladen M and McLaughlin P. Recent advances in musculoskeletal physiotherapy for haemophilia. Therapeutic advances in Hematology 2018. 9 (8) 227-237

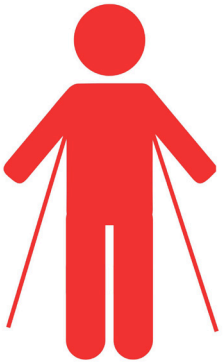


Achieving the extraordinary together



Why we go on and on about you

USING CRUTCHES AFTER A BLEED



...even if it is a minor one

Why we go on and on about you using crutches after a bleed is because the advice we give is based on the most current and available research that we are able to access. Behind the scenes we are keeping up to date by reading journal articles on human and lab-based findings of studies, extrapolating principals from similar fields (for example healing principals in sports medicine), collaborating with our colleagues world-wide, and drawing from our extensive experience. We encourage dialogue and questioning why we make our decisions and are happy to share our knowledge with you.

We recommend NO weight-bearing on a bleeding joint. The following aims to give some insight into why we make this recommendation. The literature demonstrates that we should not weight-bear on a bleeding joint. AT ALL. When it is bleeding (which may be longer than you realise). That means not "its just 5m to the bathroom", or "I'll rest it after I just do X". There are two reasons for this.

1. Protection of the joint or muscle from re-bleeding.

We want to protect the bleeding area from a) more pain and from increase in bleeding (and swelling) and b) to prevent a re-bleed. We know that putting a muscle on stretch or in full contraction when it has blood present, hurts. We know that it hurts to put a joint that is bleeding in the 'closed-pack position' where the bone ends of the joint are in the closest proximity to each other, and it similarly hurts at the ends of its range of it movement (fully bent or fully straight). In order to weight-bear it is usually put into this position. So we protect the joint or muscle in a position of comfort, usually around the middle of its range to reduce pain.

At this time of bleeding the lining of the joint (synovial tissue) increases to try and absorb the blood quickly and more effectively. It is able to do this but in this state it occupies more space than it usually would in the joint and if you walk on it there is more risk of 'pinching' it between the bone ends or other structures within the joint. This will cause more bleeding. Additionally we know that the clot is forming but may be tenuous (that is what the majority of bleeding disorder medication aims to do as an end result- to keep the clot stable and not breakdown). Weight-bearing on an 'immature' or not yet stable clot may similarly break it down and result in more or 're-' bleeding.

2. Ensuring no forced-load occurs when there is blood in the joint

Research in cells and in animal models has demonstrated that putting a forced load (eg weight-bearing) on cartilage in joints in the presence of blood increases damage to the cartilage more than when it is unloaded (not-weight-bearing). Damage to the cartilage effects the incidence and rate of osteoarthritis.

How-long do I rest for?

The million dollar question! It is essential for weight-bearing to be gradually reinstated, as of course the benefits of movement and weight-bearing are vital for healthy joints and muscles. In general we aim to optimally load the joint when the risks have been negated. In very general terms we allow some partial weight-bearing once the joint can go through its full range of movement completely pain free. Once some weight on the limb is painlessly tolerated the load can be increased.

Every person and every bleed is different however and we recommend for each bleed, even though medical treatment may be at home, a full and individualised assessment and return to function with a physiotherapy consult; please call the HTC physiotherapist for this, it may be able to be advised over the telephone or you may best benefit from a physiotherapy appointment.

On a final note, the same principals apply for bleeds in the upper limb. Whilst gait aids are not needed for the arms (although if you use an aid for the legs this may need to be temporarily ceased), a temporary disuse of the affected arm is prescribed for all the same reasons. We use our arms constantly and do put pressure and essentially do weight-bear on them (consider getting up from the ground or a low chair).

Abi Polus
Musculoskeletal Physiotherapist
Bleeding Disorders
Alfred Hsopital

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Stephensen D, Bladen M and McLauglin P. Recent advances in musculoskeletal physiotherapy for haemophilia. Therapeutic advances in Hematology 2018; 9 (8) 227-237
Hooiveld MJ, Roosendaal G, Jacobs KM et al. Initiation of degenerative joint damage by experimental bleeding combined with loading of the joint: a possible mechanism of hemophilic arthropathy. Arthritis Rheum 2004; 50: 2024-2031

LOOKING AFTER CHILDREN WITH A BLEEDING DISORDER

A CONFERENCE REPORT

Being the mum of an almost three years old severe A haemophiliac, freshly diagnosed (a bit over 2 years) – our learning journey is only starting.

The conference was the opportunity to learn more about bleeding disorders and make some new connections within the community. I enjoyed the conference a lot as it was very informative; meeting other families was also a big highlight as it is always interesting to share journeys with parents who are and have been through similar situations.

The session "Looking after children with a bleeding disorder" was probably the most relevant to me. It is always interesting to hear from experts and bringing some new tips back home. Haemophilia was described as a chronic illness and how it may impact the social and emotional development in children and adolescents. Young children have a very limited understanding of their condition and they might struggle to communicate if they have a bleed. My husband Ben and I have taught our son Louis from very early on the main parts of his body and the word 'sore'. We have tried to explain to him how important it is to let us know if he was in pain. We often do a body check when we change his nappy. It is getting easier these days as his communication skills have developed and he is now able to let us know if he is in pain.

One of the main tips given by the experts was communication. Communication is a key element to manage any child's condition. Maintaining a clear communication with our HTC and childcare has been crucial for us. The RCH run a morning seminar at the start of the school year for teachers and carers, we have had some great feedback from the educators. This has also helped to keep a good communication between the childcare and us.

Another tip was to communicate from early on with your child about their condition. As hard as it can be to explain to a young child that he has to have prophylaxis because his body is not producing any Factor VIII, we try to keep it short and simple. Some books are available to introduce the vocabulary around haemophilia and make it less scary for everyone.
We also involve Louis as much as we can while we treat him; for example, he helps us tidy up. Last year, he used to push his trolley (that we use for treatment) back into his cupboard; these days he wants to throw away the used needles into the yellow container... We believe any involvements big or small will be beneficial on the long term. Louis is about to turn 3 years and he is sometimes less cooperative. Screens have helped us or even telling him about the activity he will be doing afterwards so he has something to look forward to after his treatment.

The experts also advised to use words on the feelings a child might experience; it will help them to manage their emotions the best they can.

Advocating was also another important key element discussed. No one else will do a better job at advocating than the parents. We are still very early in our journey but we are learning to ask questions and challenge some ideas. As parents, we are the experts, we know our children better than anyone else. We will always try to provide a supportive secure home environment through reassurance and emotional support. We can always try our best and in our household we try not to have Louis' world revolve around his haemophilia. At the end of the day, haemophilia is a part of who he is but does not define him.

Claire Brunet
HFV Member

Celebrating RED CAKE DAY for Bleeding Disorders Awareness Week 2019

Hi! Our names are Harrison and Callum Grech and we both have severe Haemophilia A. We are in grades 5 and 2 at Hamlyn Banks Primary School in Geelong.

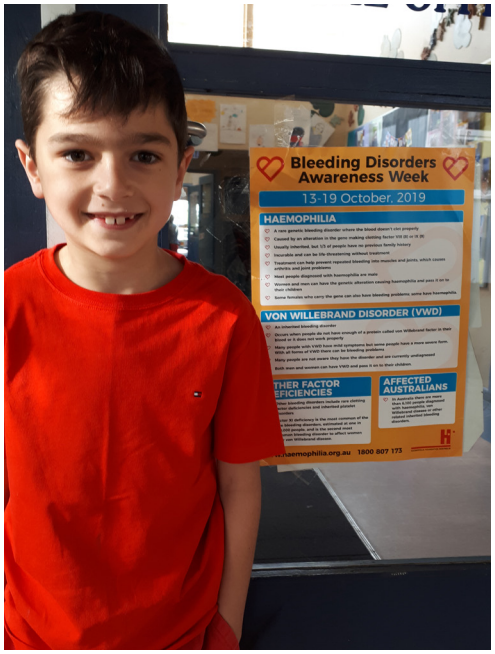
We were very excited that our school once again participated in Bleeding Disorders Awareness week. Throughout the week all grades spent time learning more about Haemophilia and how it affects boys like us, we were then asked into each grade for a Q & A session and to share our own experience, how it feels to have it, what happens and if we like having it. Some grade 5/6 grades took what they learnt into the yard and wrote in chalk key words they had learnt in the session. Our mum cried when she saw it!

On Tuesday 15th October the whole school was invited to wear red and give a gold coin donation. It was great to see the whole school joining in and supporting us. As a school we raised over $280 towards the Haemophilia Foundation, which we are so proud of. We even had the local paper, The Geelong Advertiser, come to school to photograph and do a story on us.

We can't wait to do it again next year!

Harrison and Callum Grech

(The school is amazing and has been so supportive of both boys during their journey. They arranged the week without me even asking or suggesting! So thankful to have the school and wider school community that we do! - Naomi Grech).



Understanding the impact of THALASSAEMIA

Recently Andrea and I (HFV staff) met with the staff of Thalassaemia and Sickle cell Australia. It has been interesting to learn about this genetic blood disorder, to understand the impact on their community and look at the ways TASCA works with their members. We will continue to connect with TASCA, share ideas and look at whether there would be any value in collaborative projects in the future. Below, Peter from TASCA, has shared his moving and inspiring story.

My name is Peter. I am the Acting President of Thalassaemia and Sickle Cell Australia and I have beta-thalassaemia major.

Thalassaemia is a genetically inherited blood disorder that reduces the production of haemoglobin, a protein that carries oxygen in red blood cells. This leads to less red blood cells being produced. The primary complication is anaemia, which if untreated, could lead to death.

For treatment, I attend Monash hospital every three weeks and receive three units of blood transfusion. I also see a handful of specialists which include haematologists, endocrinologists and cardiologists.

Living with thalassaemia is not a simple undertaking and many struggle with the treatment. Some choose not to disclose their status to their family and friends. I have had to learn the hard way to accept my condition and work hard to keep myself healthy.

As a child my instinct was to rebel, I didn't enjoy the treatment and attending the many medical appointments. In primary school, I could recall my name over the loudspeaker, asking for me to come to the school office. In those days the district nurse came to visit us for a crossmatch, where samples of blood are taken to match with donor blood. I still remember the feeling of embarrassment at those times when I was called to the office.

One of the side-effects of constant blood transfusions is the iron build up in the body and causes organ damage. Chelation therapy, which removes the iron, is vital to overcome this. For me, this involves injecting Desferal, an iron chelator, for 10 hours overnight 5 to 6 times a week using an infuser. Many patients now use an oral chelator called Jadenu which is a lot easier to administer. I did try this for a short period. Unfortunately, this caused further problems including kidney issues and excessive calcium excretion causing constant trips to the emergency department to remove kidney stones, a common side-effect.

My older brother, Jim, also had beta-thalassaemia major. My parents didn't know that they were carriers when they got married. If they had been married in Greece or Cyprus, a blood test would have been mandatory, and the risks would have been known. There was no such initiative in Australia and as such when Jim was diagnosed it was a shock to them.

Jim and I were of the same blood type, so when we were transfused, it was just the luck that Jim contracted Hepatitis C and I didn't. This was common amongst our community and many thalassaemia patients are still living with the blood-borne viruses contracted through contaminated blood supply in the 1980s. The stigma of having a blood-borne virus further adds to both physical and emotional issues associated with having a genetic blood disorder.

My brother was always looking on the bright side of life and I looked up to him. Jim didn't start chelating until he was in his early teens and the excess iron from all the blood transfusions he had since birth had caused irreparable damage to his organs. At the age of 25, he died of a cardiac arrest. He was my older brother and

my mentor.

My mother always blamed herself for our condition. She took it hard, as we all did. My mum was fragile after Jim's death, and soon after, she was diagnosed with bipolar disorder. Mum also suffered from manic depression and was admitted to the hospital for intensive treatment on several occasions.

The truth was, at this time, I could not cope with what was going on. My father was in denial and decided to work many extra shifts to keep his mind off the realities going on at home. At the time, my sister Christina was also heavily pregnant and starting a family of her own. (Christina is not a carrier of thalassaemia, nor are her 2 children.)

I let my health suffer and I stopped treatment. Iron started to build up in my organs, especially my heart. Before long, I was admitted to the hospital's coronary care unit as I was near a congestive heart failure with a severely dilated heart.

I can remember calling mum, who was in the psychiatric ward at the other end of the hospital, telling her I had the flu and that's why I wasn't visiting her. Even in her condition, she found out I was in the same building as her. From that day on she didn't leave my side. She made sure I underwent all the required treatments and looked after myself.

Professor Don Bowden, my haematologist at the time, came to see me and was brutally honest. He told Dad and me that my chances of survival were 50/50 at best. My only option was to chelate. So, I chelated around the clock for many months continuously to try to reverse the damage.

I was lucky. My health improved. To this day, medical staff use me as an example to medical students, junior staff, and even other patients to the importance of adhering to chelation treatment.

Sadly, mum never recovered. In 2005, she took her own life. This devastated me but also proved to be a turning point in my life. I decided then and there to make the most of what God has given me. I began to study, travel, build new friendships, and have a positive outlook on life just like Jim and Mum would have wanted.

I always challenge myself and strive to exceed expectations. I now work as an Early Parenting Practitioner and also as a facilitator for playgroups and parenting services. I am also a consumer advisor for the Monash Health Blood Committee. I have also become a mentor to younger patients or those going through a difficult time and a leader within the haemoglobin disorder community.

Peter
TASCA

Thalassaemia and Sickle Cell Australia is a not-for-profit organisation that advocates and supports patients and families living with genetic haemoglobin disorders. We raise awareness in the community through public events, social media, and information seminars. If you would like to know more about who we are or would like to support our work, please visit our website: www.tasca.org.au

Carrier screening for genetic haemoglobin disorders are free and simple in Australia and can be requested from your GP. Get tested and know your risk today.

Thalassaemia and Sickle Cell Australia

Unifying Support with Genetics

Supporting World AIDS Day at The Alfred

This year The Alfred Hospital supported World Aids Day by providing an information booth with HIV Awareness material for the staff, patients and visitors of the hospital. The theme this year is Every Journey Counts working towards eliminating stigma for those people living with HIV.

world AIDS day
DECEMBER 1

EVERY JOURNEY COUNTS

For more information and resources please go to WWW.WORLDAIDSDAY.ORG.AU

CELEBRATING 1000 PATIENTS ON ABDR AT THE ALFRED

This is a picture is of our multi-disciplinary team at Alfred health celebrating (with cake!) the registration of reaching 1000 patients on the ABDR (and counting).

The ABDR helps us deliver the best care for our patients and we are working tirelessly to capture everyone with a bleeding disorder to offer them the opportunity to be registered.

ABDR
Australian Bleeding Disorders Registry

HAEMOPHILIA FOUNDATION VICTORIA

MENS HYDROTHERAPY PROGRAM 2020

EXPRESSIONS OF INTEREST

WE ARE LOOKING INTO THE VIABILITY OF RUNNING HYDROTHERAPY SESSION/S IN 2020.
IF YOU HAVE ANY INTEREST IN THIS TYPE OF PROGRAM PLEASE EMAIL JULIA@HFV.ORG.AU

Please share this with others with bleeding disorders!
If we do not receive expressions of interest it will not be pursued further.

EXPRESS YOUR INTEREST NOW!!!

WE HAVE ONLY RECEIVED A COUPLE OF EXPRESSIONS OF INTEREST SO TO DATE, SO PLEASE CONTACT US IF THIS PROGRAM WOULD BENEFIT YOU

GUYS WITH BLEEDING DISORDERS

are invited to attend the Haemophilia Foundation Victoria

2020 MEN'S RETREAT

massage relaxation meditation mindfulness

FRI 20 – SUN 22 MARCH, 2020
LOCHINVER FARM HOMESTEAD, CARISBROOK
FOOD & ACCOMMODATION PROVIDED BY HFV

Bookings essential through
www.trybooking.com/BHEUJ
For more information
please call HFV on 03 9555 7595

Andrew - Climbing in New Zealand

ON TOP OF THE WORLD

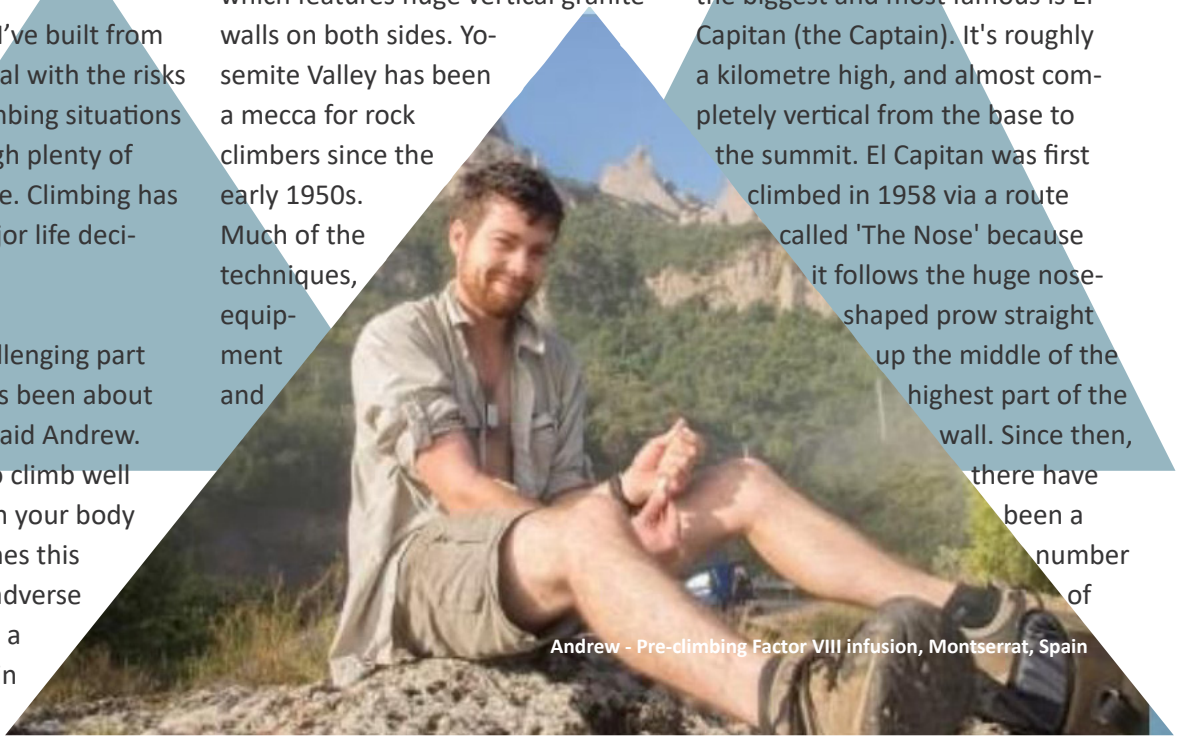
Andrew and Scott both have severe haemophilia A, with associated degenerative osteoarthritis of the ankles. They discovered rock climbing as an activity that offered a way to experience the outdoors without the physical barriers associated with many mainstream sports.

'The confidence that I've built from knowing that I can deal with the risks and challenges of climbing situations has helped me through plenty of other challenges in life. Climbing has also guided some major life decisions,' said Scott.

'For me the most challenging part of climbing has always been about mental self-control,' said Andrew. 'In order to be able to climb well you must control both your body and your mind. At times this has meant enduring adverse weather like being on a climb at Pierces Pass in winter and having ice crystals rain down on top of you, or forcing myself to focus through dehydration and heat stress climbing at Montserrat in Spain, or dealing with terrifying loose rock on screen slopes in the Dolomites of Italy. All of these things are small challenges that must be overcome to continue to improve and fully appreciate the experience of rock climbing.'

Yosemite is a world-famous national park located in the Sierra mountain range in California. The best-known part of the park is Yosemite Valley, which features huge vertical granite walls on both sides. Yosemite Valley has been a mecca for rock climbers since the early 1950s. Much of the techniques, equipment and culture of modern climbing evolved in Yosemite. The valley is best known to climbers as the home of 'Big Wall' climbing, which refers to climbing long routes on vertical walls that take more than one day to complete. Nights are spent living on the wall, either on small natural ledges, or in 'portaledges' which are a kind of hanging tent that is suspended from the wall.

While there are many rock formations in Yosemite Valley that lend themselves to big wall style climbing, the biggest and most famous is El Capitan (the Captain). It's roughly a kilometre high, and almost completely vertical from the base to the summit. El Capitan was first climbed in 1958 via a route called 'The Nose' because it follows the huge nose-shaped prow straight up the middle of the highest part of the wall. Since then, there have been a number of other climbing routes established on El Capitan, but the Nose is still the most coveted by climbers from around the world. It's highly technical and involves climbing a series of crack systems, using ropes and gear both to prevent falls and to aid in



Andrew - Pre-climbing Factor VIII infusion, Montserrat, Spain

upward progress. Most climbers take between 3 and 5 days to climb the Nose.

'Climbing El Capitan has been a dream of mine since I started climbing, but its only really become a specific goal in the last five years,' explained Andrew. 'In 2013 I spent a few weeks climbing in Yosemite with my partner Laura. We climbed a lot of the easier routes in the Valley, but at the time we weren't really ready for the bigger walls. One of the climbs we attempted involved spending a night on the wall, but we had to retreat when we realised that we didn't have the technical skills to get up a particularly difficult overhanging section of rock. Since that experience I've spent a lot of time learning the skills necessary to climb big wall routes. In the back of my mind I've considered all the climbing I've done for the last several years to be training for returning to Yosemite to climb El Capitan.'

Over Easter Andrew and Scott did a training climb at Ozymandius at Mt Buffalo National Park in Victoria. It's located on the north wall of the Mt Buffalo gorge, which is 300 metres high.

'Planning for the training climb and Yosemite, and especially with haemophilia, can be logistically complicated -, planning is important,' said Scott 'Having a plan for managing our factor supplies and infusions will also be critical. I've learnt from personal experience that I need daily infusions of factor VIII to prevent bleeds when I'm doing something physically strenuous like climbing. We'll bring enough supplies with us to ensure that we avoid bleeds, plus extra in case of emergency. Both of us are used to performing intravenous infusions, so we will be capable of treating each other in an emergency.'

Reprinted with permission from HFA and Andrew and Scott Godwin

We are delighted to hear that Andrew and Scott have both returned from El Capitan and we'll have the 2nd installment of their incredible journey to share with you in the next edition of The Missing Factor.

What aspirational and inspirational people we have within our commuty!

Please take the time to view some of their adventures on Youtube (see link below). It is a fascinating watch!

Scott (leading) and Laura (belaying) on Ozymandius - Mt Buffalo, Victoria

www.youtube.com/watch?time_continue=5&v=jDsOmJDYj_4

REDCLASSIC

Supporting the Bleeding Disorders Community

2019 HFV RED CLASSIC

THANK YOU for all your SUPPORT

Walk for BLEEDING DISORDERS

What a great turnout we had for our 2nd Walk for Bleeding Disorders Awareness. It was wonderful to see so many supporters all dressed in red come and join us for a lap of Albert Park Lake. We had a great contingent of four legged friends also join us on the day which was wonderful to see!

We were concerned that the weather would not be favourable but luckily the rain stayed away and it was a very pleasant afternoon. We had a few helpers running the bbqs so our walkers were treated to a sausage or two on their return.

We have plans to make next years walk BIGGER AND BETTER with more structure and an increase in awareness, health promotion and an opportunity to fundraise. We hope we can count on you for your continued support! (and we're always happy to receive feedback and ideas to help improve all our events).

Thanks again,
The HFV Team

ASK US

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

As I get "older" I've noticed my body doesn't feel as strong or recover as it once did. What should I do?

We all get older and our body does "age" in different ways which are a normal part of life. These can be influenced by many aspects of our living such as our diet, exercise, genetics, mental wellbeing, pre-existing conditions, prescribed medications and treatments, and our lifestyle choices – recreational drugs and alcohol consumption, risky behaviour activities that we are not physically set up for etc. It may be an idea to consider your lifestyle and assess if you are as active as you previously were? Are there changes that you can make yourself that may benefit you? For example increase sleep, regular exercise, a healthy diet? Have you discussed any concerns with your friendly HTC physiotherapist, haematologist or rheumatologist? There are of course services around to help too.

a/ Do you have a good relationship with a GP or even been to a GP for your non-bleeding disorder related health care?

We recommend all clients/patients have the backing of a local GP in addition to attending to your annual review and booked clinics as needed at the Alfred HTC. If you feel "out of sorts" and it's not bleed related, please attend and consult with your GP or local medical practice. They will be able to also contact the HTC if they have questions about your bleeding disorder.

b/ If you think it's an acute bleed related issue:

Consult the HTC nurses, present to the Alfred Emergency department or closest regional Emergency department if you live out of metro area. If it is a chronic bleed related issue, such as ongoing swelling or pain in the absence of acute bleed symptoms, or regular bleeding in a certain joint contact the HTC and book in to see a member of our team, we can direct you to who is best to see over the phone and make an appointment for you.

c/ Do you think it's musculoskeletal in nature, feeling like it's a pain that does not resolve in a few days with RICE?

Discuss with the HTC physiotherapist if they are free, and book an appointment with the physiotherapist at the HTC. Physiotherapy have a half day of sessions 4 times a week Monday to Thursday at the HTC at present.

What if I need help or services? (You do need to be an Australian citizen first and foremost).

1/ under 65 years of age

- See your GP or HTC medical officer/ social worker
- Think about what is the problem and what you think would help out?
- What's your goal or need?
- Contact your local council depending on what you need. Ask to speak to their Home and Community Care/Welfare services
- Consider applying to the National Disability Insurance Scheme, and an Access Request application will be sent to you.
- Visit this link https://www.ndis.gov.au/what-consider-i-apply/am-i-eligible
- call 1800 800 110 to discuss and arrange for the initial registration.

2/ 65 years of age and over

- See your GP or HTC medical officer/social worker
- You will need to apply to your local council depending on what you need
- Have you had or thought about an Aged Care assessment?
- You may be eligible for a package of in-home care and services
- Contact the MyAgedCare 1800 200 422 or
- login to the link https://www.myagedcare.gov.au/

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

HFA National Volunteer Award 2019

Celebrating 10 years of Paint the Town RED

We are exceedingly lucky to have many active community focused members at HFV. There are many that get involved in fundraising throughout the year and fund raise for HFA's RED CAKE DAY to celebrate Bleeding Disorders Awareness Week.

We are very proud of Donna Field and her family (Grant, Emma and Adam). The Field's have been involved in raising funds for HFA and awareness of bleeding disorders in their home town of Neerim South for 10 years. Donna makes hundreds of cupcakes for the event, their local butcher donated all the sausages, tip top donate the bread, many other locals assist with baking and supporting the event with donations.


Donna Field with Sharon Caris

Donna works for Neerim District Community Bank which is part of the Bendigo Bank. Donna has been so well supported by her employers in her fund raising efforts throughout the years. Donna also initiated a national fundraising program through the Bendigo Bank which has brought much needed funds to our community.

We are so inspired by Donna, her commitment, drive and determination and would like to thank her for all that she does for the bleeding disorders community. We'd also like to thank Grant, Emma and Adam as it is truly a family effort with all hands on deck!

Donna was recently awarded a Volunteer of the Year Award at the National Conference in Sydney. Unfortunately, Donna could not attend the conference but received the award from Sharon Caris, HFA over a dinner to personally thank Donna and her family.

The Haemophilia Foundation Australia Volunteer's Award is given to a person who has made a significant contribution at national, state, territory or regional level or for a specific event. The award has been presented to Donna Field in recognition of the 10th Anniversary of Paint the Town Red in Neerim South, and for her long terms commitment to raising funds and community awareness during Bleeding Disorders Awareness Week.


Grant, Emma, Adam and Donna

HFV's AGM & Christmas Picnic 2019

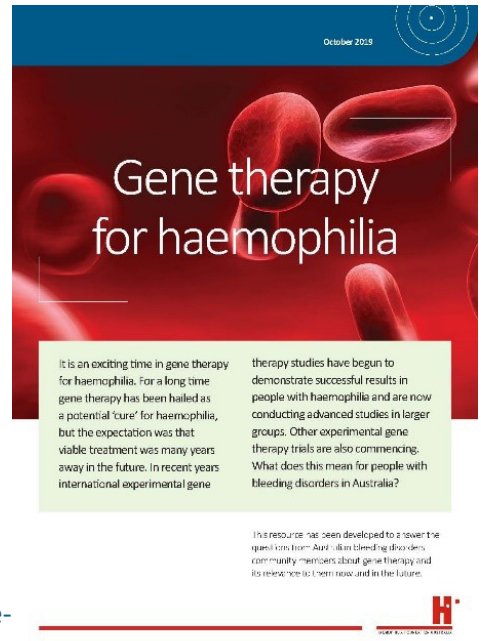
Thank you to all who came to our annual Christmas Picnic and AGM. It was a lovely day out, a wonderful chance to reconnect with each other and a great opportunity to share our HFV news from throughout the year. If you couldn't make it we hope you will be able to attend the HFV Community Camp (it is early this year 14-16th Feb) to CONNECT, SUPPPORT AND EMPOWER in 2020!

New gene therapy resource

Do you have questions about gene therapy for haemophilia?

We are pleased to announce the release of HFA's new resource ***Gene therapy for haemophilia***, which was developed to answer the questions from our community:

- What types of gene therapy are used in haemophilia?
- How does gene therapy work?
- Is it a cure?
- How safe is it?
- Who can have gene therapy?



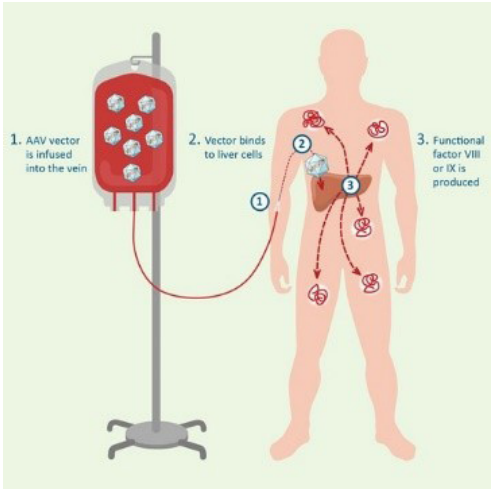
The information includes diagrams to explain simply how genes and gene therapy work.

HOW TO ACCESS IT

Gene therapy for haemophilia is available in multiple formats:

- As a downloadable PDF on the HFA website under PUBLICATIONS (https://tinyurl.com/HFA-gene-therapy-pub)
- As web pages under ABOUT BLEEDING DISORDERS (https://tinyurl.com/HFA-gene-therapy)
- Print copies are also available from HFA, local Foundations and your Haemophilia Treatment Centre.

A print copy has been included in this issue of HFV's The Missing Factor.



OUR THANKS

We would like to thank the bleeding disorders community members and expert reviewers who made valuable contributions to this resource, and to our designer, Ray Hehr, for his clear and thoughtful diagrams.

In December 2018-January 2019 HFA conducted a national community survey to find out what questions the bleeding disorders community would like to have answered. This resource was developed to answer those questions.

This resource was funded by an education grant from BioMarin.

MORE INFORMATION

To find out more about **Gene therapy for haemophilia** or to order copies, contact HFA:

E: hfaust@haemophilia.org.au
T: 1800 807 173 W: www.haemophilia.org.au

HFV Noticeboard

To post a message on our noticeboard, please email our HFV office at info@hfv.org.au or call 9555 7595

HAEMOPHILIA FOUNDATION VICTORIA
INVITE ALL PEOPLE LIVING WITH BLEEDING DISORDERS & THEIR FAMILIES TO ATTEND OUR

2020 COMMUNITY CAMP

FRI 14 – SUN 16 FEBRUARY

ADANAC CYC, YARRA JUNCTION

Please note that the 2020 Community Camp is early this year (14th - 16th February) so please put the dates in your diary

Book online through Trybooking. www.trybooking.com/BEPSS (You can also book now but pay later if you prefer).

FOR MORE INFO GO TO WWW.HFV.ORG.AU
BOOKINGS THROUGH WWW.TRYBOOKING.COM/BEPSS

ROYAL CHILDREN'S HOSPITAL

HAEMOPHILIA TEACHERS SEMINAR 2020

$33 PER TEACHER

You are invited to attend the 17th Haemophilia Teachers Seminar presented by the Haemophilia Treatment Centre Team at the RCH. Supported by Haemophilia Foundation Victoria

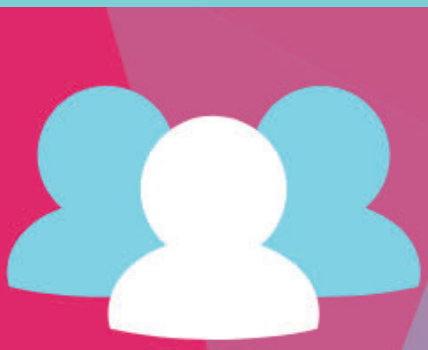
(REGISTRATION 8.30AM -9.00AM)
9.00AM - 12PM FRIDAY 21ST FEBRUARY
ELLA LATHAM THEATRE,
GROUND FLOOR MAIN BUILDING
ROYAL CHILDREN'S HOSPITAL

Bookings Essential through TryBooking by 15th Feb
www.trybooking.com/BGTRR
or search haemophilia in trybooking

Speakers:
Dr Chris Barnes, Janine Furmedge (Haemophilia Nurse), Nicola Hamilton (Physiotherapist) and primary & secondary aged students with haemophilia

HFV MEMBERSHIP ENGAGEMENT SURVEY

THANK YOU



Many thanks to all our members who took the time to complete our online survey.
We are currently analysing the data and will implement recommendadtions in due course.
Congratulations to Joan Bates, our movie tickets winner for completing the survey!

HAEMOPHILIA FOUNDATION VICTORIA INC
13 Keith Street
Hampton East VIC 3195
Phone: 03 9555 7595
(Due to the NBN we no longer have a fax number)
info@hfv.org.au
www.hfv.org.au

HFV is committed to Child Safety.
Our Child Safety Statement is available for review on our website www.hfv.org.au

The Missing Factor is the official publication of the Haemophilia Foundation Victoria (HFV) with four issues annually.

HFV is funded through the Department of Health and Human Services under Blood Borne Virus Sector - due to the historical impact of contaminated blood products on the haemophilia community. HFV supports our diverse community and our magazine reflect topics that impact our community including bleeding disorders, BBVs, mental health and positive health promotion.

Editor: Julia Broadbent

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Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Jane Portnoy | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist
Frankie Mullen | Physiotherapist
Catherine Haley | Physiotherapist
Diana Harte | Psychologist
Debra Belleli | Data Manager

HFV MEMBER SERVICES & PEER SUPPORT

Membership Annual Fees:

$33.00 Standard family membership
$16.50 Concession / Allied
$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.

Other Subsidies:

- 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.

The HFV Office:

The office is usually open from 8.30 am to 4.30 pm Monday to Thursday. If you plan to come to the office, we suggest you ring ahead to check if the office is staffed.

We are located at 13 Keith Street, Hampton East VIC 3188.
Phone: (03) 9555 7595
Website: www.hfv.org.au Email: info@hfv.org.au

MEN'S GROUP

Our current group meet for their Annual Men's Retreat – a much needed weekend away that included massages, relaxation and meditation. In 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 usually get to enjoy an event with a twist. A recent event our ladies spent a day at the Peninsula Hot Springs and enjoyed a beautiful meal together.

They have previously learnt circus skills, African drumming, attended relaxing massages, high tea on the Yarra and lunch on the Tram Restaurant…to name but a few.

YOUTH GROUP

The Youth Group aim to meet up a few times a year usually based around an activity like laser skirmish or bowling and then head out for 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!

The initial impact of haemophilia can be a traumatic and stressful time in our lives and interaction with other grandparents can be a reassuring and rewarding experience.

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.
Previously our Boys Toys events have included fishing trips, Go-Karting, Laser Tag and Tree Top Adventures.

Masquerade Ball 2020

SAVE THE DATE

SATURDAY 17th OCTOBER 2020

HAWTHORN ARTS CENTRE

CALL FOR HELP! Anyone wishing to be involved (a little or a lot) in the lead up to the ball or to assist on the night, please contact the HFV office on 9555 7595

HAEMOPHILIA FOUNDATION VICTORIA