HAEMOPHILIA FOUNDATION VICTORIA INC

SPRING 2019

THE MISSING FACTOR

HAEMOPHILIA
a small obstacle in the journey of life

REFLECTIONS ON TWINNING WITH MYANMAR

STILL TIME TO BOOK!
Australian Conference on haemophilia, VWD & rare bleeding disorders
10 -12 OCT SYDNEY

Challenging the Status Quo

Photo by Rijan Hamidovic from Pexels

connect • support • empower

SPRING 19

Haemophilia Foundation Victoria acknowledges the support of the Victorian Government.

DIARY *DATES*

OCT

10-12 National Conference

13-19 Bleeding Disorders Awareness Week

20 Red Classic (Walk for Bleeding Disorders)

NOV

17 AGM & Christmas Picnic- Melbourne Zoo

DEC

23 HFV Office Closure until 20th January

FEB 2020

14-16 Community Camp 2020

MAR 2020

20-22 Men's Retreat

PRESIDENT'S REPORT

Spring is so close I can feel it...for those with hay fever you can almost feel the sneezes.

As always, there's a lot going on at HFV. Our very successful regional visits have now also included outer metro areas and we have had some successful evenings shared with our community.

Cranbourne was a great night and a chance to reconnect with a very important family from HFV being Ann Roberts and some of her family. As many will know Ann did so much for HFV and I must always give credit to the great agency she led for so long before I stepped into the President role, along with other great presidents too. It was so lovely to spend time with Ann, Danny and Chantel to update them on all the great things happening in haemophilia care and HFV more specifically. We also welcomed new faces and that was a real treat too. We have new members that have joined and as always it was so special to take time to chat and hear about their challenges. We hope they will also join us for upcoming camps and activities such as the fast approaching AGM.

The next night out was in Epping. Again a great night and we were able to connect to more new members and families. All experiencing their own challenges but already to share their story and have a bit of fun.
Not all faces were new, and we also reconnected from some friends from the camp. Great to see them again.
HFV booked an interpreter to ensure we were able to communicate with some attending. How great is that to include a diversity in language as well as travelling around the state.
The community events provide the fuel we need to stay motivated.
Thank you to all that made the effort to join us especially in the cold winter evening. Thank you also to the staff and fellow committee members that also come for the fun. If you haven't been to one yet, please make sure you join us at the next visit.
The community picnic and AGM is always a great day out so keep your eyes posted for details... at Melbourne Zoo this year!

I have also been busy supporting our neighbouring state in South Australia. Sadly, SA lost their association some years ago and there is a small group of dedicated people trying to again form an organisation. I was able to meet with them and share some of the ways HFV has streamlined some practice to support the work they are trying to do. We wish them well and hope we will be able to support them to grow moving forward.

Across the Tasman we are also speaking with HFT in Tasmania. Due to the population Tasmania are not able to have camps and events such as HFV. We have extended the invitation to both SA and Tassie for many years to attend our camps and we are hopeful that there is some interest for

HFV MEMBERSHIP ENGAGEMENT SURVEY

PLEASE HELP HFV IMPROVE OUR MEMBER ENGAGEMENT BY COMPLETING THIS IMPORTANT SURVEY

Please complete by the end of Bleeding Disorders Awareness Week - 19th October 2019

All completed surveys go into the draw to win 2 GOLD CLASS MOVIE TICKETS!!!!

Please go to https://bit.ly/2ztTutA

2020. We hope this will happen as we would love to extend our haemophilia family across borders and the waters. Stay tuned.

At HFA we were able to host a dinner for some of the special guests from WFH that were in Melbourne for a conference. The conference was a huge success and as well as HFA doing an amazing job showcasing our agencies, we were also able to share a meal with the president and other VIPs and enjoy the delights of Melbourne together.

As I write this I am preparing to fly to Vietnam at the end of this week. I am very honoured to attend an Asian Haemophilia Network workshop in Hanoi where I will learn so much from some amazing people in our international community. Again, I will meet with WFH executive but just as importantly hear from others in our region about the other twinning and positive programs that are happening. I will do a short presentation about Australia and the tendering process for our treatments as well connect with many that I hope to build relationships with and enrich the work at HFV. I am very privilege to have this opportunity and hope to do those that stand with me proud. I will certainly be writing an article for the newsletter to come so hope you take time to enjoy.

I am then taking a break from HFV and the other madness of life for an extended holiday. Sharron and Dan from committee will attend the HFA AGM on behalf of HFV and I am sure will do an amazing job. I will sadly miss the National Conference but hope many of you are going to be there. This will be a fabulous event and I am so sorry to not be back in time. I look forward to hearing all about it.

I will be back however for our AGM on 17th November. I hope many of you will be there. The AGM is an important event in our calendar. We will report back to you, our membership, on the work we have done in the past year and we encourage you to attend and hold us to account. You are the voting people that can change HFV and we would love anyone to nominate for committee if you are interested. We do teleconference meetings so rural and regional people or those with life demands that make attending difficult are very much encouraged to join the team. If you are interested, please contact the office for a chat. Happy to find a new president anytime!

Speaking of committee, we are looking for a new treasurer. Zev has made a difficult decision but has decided to not renominate for next year. Zev has done such an amazing job and he will be very deeply missed. The good news is Zev will continue to support the Men's Retreat so we are not losing him completely. On a personal note I do want to acknowledge Zev's hard work and the support he has given me. Zev has been nothing but encouraging of my work and I will miss our chats.

A special mention at this time of the year for Andrea in our office. Most will not know nor appreciate the work that goes on behind the scenes to keep HFV ticking over. Julia produces the amazing newsletter and continues to look after all communications etc. However, Andrea has the much less profiled role of preparing financials for auditors, pulling together annual reports for government requirements as well and keeping committee including me on track. Moreover, Andrea must complete reports to our funders at DHHS. These reports are comprehensive and are challenging in capturing all the amazing work that happens and making it fit into the needs of the department for acquittals and to be signed off. I can support a very small part of this work, but Andrea spends hours in reporting and finalising the critical work we need to keep government satisfied with HFV. I am very much in awe of Andrea's skills and we are truly lucky to have both her and Julia in the team. Between them both, as the dynamic duo, they make me look so much better than I am and I sincerely thank them for their extraordinary efforts. Recently, I was able to report back to the committee after their performance appraisals and no surprises to hear we were all in agreement that they need to be acknowledged for their commitment and hard work that continues to go beyond what we really have a right to expect. The good news is they are both hopefully staying for more at HFV, so I look forward to the next exciting year as we plan for the AGM and beyond.

Lots going on and lots to look forward to on the horizon. National conference is worth attending and there are some subsidies available through both HFA and HFV. The AGM and family picnic is so much fun we would love to see you there. Again, it is time to nominate for the committee so if you have any interest please talk to us. We are especially keen to speak to any members with haemophilia themselves as we need to keep your voice at the table. I am signing off for a few months and thank Sharron for stepping in and holding the fort with the team. Look forward to hearing all the news and updates on my return and seeing lots of you at upcoming events.

Kindest regards,
Leonie Demos

LIVE WELL FUNDING

HAEMOPHILIA FOUNDATION VICTORIA

What's it all about?

The purpose for the Live Well Grant is to provide an opportunity to assist with an expense that would otherwise not be possible without assistance from HFV under this program. The program aims to improve the health and well being of members. Although there is no absolute limit, as a guide, previously approved Live Well Grants have generally been for amounts of between $50 and $500.

There are a few important points:

• Live Well is available to current HFV members. (The membership fee may be waived due to financial hardship)
• Any application received will be de-identified meaning only the Executive Assistant (Andrea McColl) will know the name of the applicant
• Those with bleeding disorders and their carers can apply
• Amount guide $50 -$500

What has been applied for previously, including partial subsidies:

- Wheelchair modifications
- Wheelchair hire
- Swimming lessons
- Crutches
- Orthopaedic mattress
- Handrails
- Ankle brace
- Shoe orthotics
- Massage
- Long term hospital admission TV hire

Application forms can be found on our website under services.
www.hfv.org.au/support-services/services

Connect Support Empower

HAEMOPHILIA

a small obstacle in the journey of life

Max (far left) in the Greek isles with his friends

My name is Bronwyn Grant and my family and I have been active members of HFV for many years. My family has a long history of haemophilia. Many people think that people with haemophilia bleed more profusely than those without the disease. This is not so…. they simply bleed for longer. The real cause for concern is internal bleeding ie bleeding into organs muscles or joints. The life expectancy of someone with severe haemophilia in 1960 was less than 20 years old. In the 1970s freeze dried powder concentrates containing factor VIII were invented which revolutionised haemophilia care as patients could treat themselves at home rather than having to go to hospital all the time. In the 1980's the haemophilia community was devastated to learn that blood products had been contaminated with HIV and also hepatitis C. Many many people with haemophilia died from AIDS through the use of contaminated products. I had a cousin who died from AIDS when he received a HIV contaminated batch back in the 80's. The 1990's saw the manufacture of synthetic recombinant factor VIII rather than a plasma derived product which was much safer to use. The products manufactured today are very safe and ironically my sister worked at CSL producing the blood products that Max, our son, was to use in his treatment. Max was even invited to do a demonstration of using the product for staff to make it more meaningful for them!

I was blessed to come from a very big family (catholic of course). My great grandfather had haemophilia and despite being born in the era when the treatment was very poor, he lived until he was in his early 60s. He died while having his appendix out. My mum was a carrier of the disease. My mum had three boys older than me and then three girls. The two older boys did not have haemophilia but my third brother David did. He was born in 1952 and unfortunately treatment for the disease was not good at this time. He died when he was two years old after he fell off the front gate whilst using it as a swing. Unfortunately, he landed on his head and suffered a cranial bleed which is basically bleeding on the brain. He died the day before his second birthday after being kept alive in an iron lung for a few weeks.

Treatment in those days was by a whole blood transfusion. Mum did not talk about this period in her life very much as it was obviously too painful. However, after David died, she went on to have three more children…all girls. I am the eldest of my sisters. As my two brothers did not have haemophilia, I had no experience with haemophilia growing up so to me it was just something that I knew was in my family history but I had no experience with first hand.

After I got married, very naively my husband Dean and I decided to start a family without doing much research at all into the prospects of having a child with haemophilia. I guess we thought we'd just take our chances and hope for the best. I didn't even know if I was a carrier or not. I only knew I could be. Thinking back I can't believe that I was so naive. I became pregnant with my daughter Emma...so far so good. A perfect pregnancy with no complications. By this stage I knew that I was a carrier through having tests while pregnant with Emma. Okay, so I had the most perfect child, easy and good in every way. We said to ourselves, if we could do it once we could do it again and Emma was desperate for a little brother or sister. I had a one in four chance of having a child without the haemophilia gene. Well, it was not to be. I became pregnant again and after having foetal blood testing at 18 weeks found out I was having a little boy and he indeed had haemophilia.

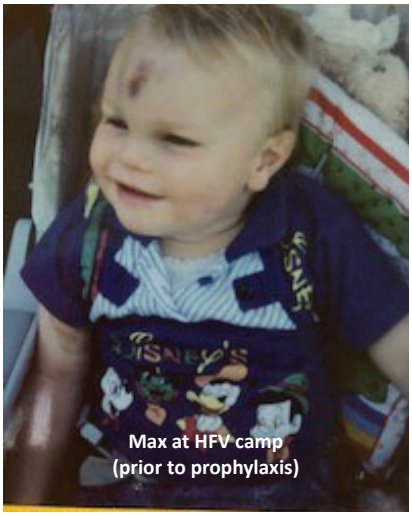
How did I feel? Scared frightened and very afraid of the unknown. So many different emotions were going through my head. I was

offered a termination but this was never an option for me. So, after I had calmed down and stopped crying, I decided I was going to gather as much information as I could on the disease and become an expert. So I contacted the Haemophilia Foundation who were just fantastic with giving me information. They were so reassuring and helpful and put me in contact with a family that I could discuss my concerns with. The Foundation was to prove invaluable to my husband Dean and I. When Max was small we went on many camps and became friends with other families with haemophilia. We also served on the committee for many years and to this day we still organise fundraising activities.

Back to my pregnancy with Max. It was anything but normal. At 29 weeks I developed severe placenta previa, a condition where the placenta is partially across the birth canal and can cause bleeding and miscarriage at any time. I was put in hospital where I was to stay for the next 8 weeks to be closely monitored until the birth. Needless to say I did a lot of craft work while I was laying flat on my back waiting for this baby to arrive. My doctor was more concerned about whether I was going to make it through let alone the baby. I haemorrhaged very badly one night and the doctor was very concerned that the baby was going to come early but I managed to hang in there.

The gorgeous Max Jack Grant was born at 37 weeks via c section. Mother and son were both very well and mother was very relieved to be leaving hospital. And so began life with our little son with haemophilia.

While Max was a baby everything seemed to be fine as he wasn't moving around much. He had his first infusion at 4 months when I accidentally hit his little head on the table as I was trying to get him out of his baby capsule. We didn't even know if he needed factor VIII or not but I was terrified because it was his head and we had been told beware of any head injuries as they can be very dangerous and they must be treated. Well what an experience that was. I don't know who cried more, me or Max. Lucky Dean was always the strong one and kept us from going under. Trying to find a vein on a tiny little baby through which to inject his factor VIII was just horrible. Once Max became mobile we endured many, many visits to the hospital so that he could be infused with his missing factor VIII.



Max at HFV camp
(prior to prophylaxis)

We would be in the hospital at least once a week for some reason or other. Sometimes veins would be hard to find so it could take many times to actually find a suitable vein to infuse the factor. He was even injected into his foot on a couple of occasions. So poor little Max would be screaming his lungs out. We'd be trying to hold him down while the doctor was trying to put the needle in. It was horrible and very, very stressful for everyone concerned, even the poor doctors and nurses. This was to be the pattern of our lives for the first four years of his life. I asked Max what his first memories of haemophilia were and he said hiding behind a pole at the children's hospital being terrified. Max had internal bleeding in all sorts of areas. He had bleeds in many weird and wonderful places… his mouth, fingers, toes, forearms, buttocks, knees, ankles, nose, scrotum and head. One time he fell on his head twice in the same spot on his forehead. He ended up looking like the elephant man. Sometimes the bleeds would be spontaneous and sometimes from trauma. Sometimes he would have to be admitted if the bleed was particularly bad and be put on a continuous infusion of replacement factor VIII. These times were particularly hard as not only was it stressful emotionally but I was working part time, Emma was in school and Dean had a full time job.

Fortunately, we had a fabulous support system around us in particular my mum and my mother in law who were just wonderful and would drop everything to help us out.

When Max was around three he started to get regular bleeding into his left ankle and this became a target joint with many bleeds into the same site. No sooner would it start to get better then the bleeding would start up again. He had regular physiotherapy to try and ease the problem but nothing seemed to work. It was very, very painful. Max's vein access at this time was also becoming a problem. His haematologist decided that Max needed to be on prophylactic (ie preventative) treatment ie regular infusions of factor VIII, rather than on demand treatment, to try and stop the ankle bleeds that were

Max at HFV camp

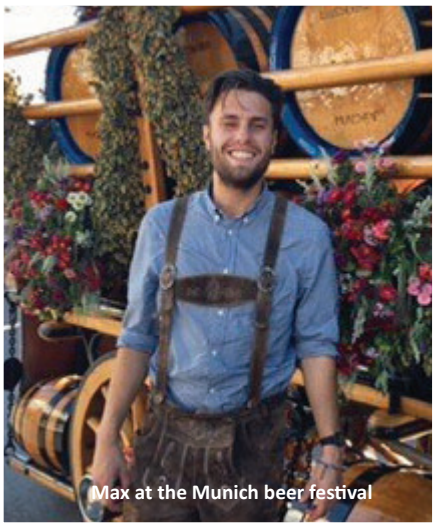
causing him so many problems. He was to have this 3 times a week. Just before his 4th birthday he was admitted to hospital for three days where an infusaport was implanted in his chest so that treatment would be easier to administer. So Max then had to be in at the hospital 3 times a week for his infusion of factor VIII early in the morning. This was a very stressful time as I often think back to how on earth we ever managed to cope but we did. Three months of this back and forth to the hospital, we thought there has to be an easier way.

The Royal District Nursing Service was just starting to offer their services to the haemophilia community. We were put in touch with the most wonderful caring nurse by the name of Sue Moore who would come to our home and treat Max three times a week early in the morning. It was so much better and less stressful for everyone with Max being treated at home.

At the end of that year we decided that it was time for us to learn how to treat Max and with Sue's assistance this is what we did. This was not an easy task as it required making sure that everything was sterile so the bathroom had to be meticulously scrubbed down. The treatment area sterilized and then we would have to gown up and glove up. We allocated one of the bedrooms as a treatment room. If anything was compromised then we would have to start again. So all this would happen before I went off to work and Max went to school. With Max being treated 3 times a week the incidence of bleeds was cut down considerably.
He started school without incidence with all the teachers being educated in what to look out for when dealing with Max. A representative from the Haemophilia Foundation also spoke to the staff. He still had bleeds but not nearly as many as before prophylactic treatment. Max's ankle was still an ongoing problem so in grade 3 after consultation with an orthopaedic surgeon a partial synovectomy was performed on Max's left ankle. He was in hospital for a week on a continuous infusion of factor VIII. Function in his ankle certainly did become a lot better and he was even able to participate in Aus Kick much to his delight. He also took up tennis and enjoyed playing in a team for many years. Max had to have his infusaport replaced 3 times as they wear out after about 4 to 5 years. This also required hospital time.

When he was 13 his haematologist Henry Ekert, thought he was old enough and mature enough to start doing his own treatment. This was a long arduous progress taking the good part of a year to perfect. Max would practice on oranges and mannequins at the hospital and even his father (not me) trying to perfect the art of trying to find a vein and then slowly being able to infuse the factor VIII into a vein. Once again a stressful time for all concerned particularly if Max could not get the vein because then it would mean a visit into the hospital.

Once Max perfected his treatment life was pretty stable. His secondary schooling was good and he was even able to go on camps as the school nurse would go as well just to oversee Max's treatment. She was a wonderful woman and a great friend to Max and was always there for Max throughout his years at Ivanhoe Grammar.
We have had quite a few bad incidences where Max has come to grief. One notable occasion was when we were on holiday in Bali when Max was 17. We went to a lovely surf beach where you had to go out to the reef in order to surf the wave break. Max and his father who fancied themselves as really good surfers decided they would go and tackle the big waves. Well, off they went and got dumped on the very first wave and ended up on the ocean bottom. They struggled into shore which was miles away. Max limped into shore and by that night his leg was swelling up big time. He had also used up most of his factor VIII that he had bought with him as we were going home within a few days. He went home before us as he was supposed to be starting an electrical apprenticeship. He didn't start the apprenticeship on time as he ended up in hospital with a major bleed into his thigh. This took two weeks in hospital to recover from.


Max at the Munich beer festival

Max's career path was a little unusual. I really thought that he would embrace a desk job but many of Max's friends chose tradie jobs and so Max decided he would give an electrical apprenticeship a go. He successfully completed this and has had hardly any time off through bleeds. He prefers to push through even if he is hurting. He has a very strong work ethic.

From time to time he does have bleeds but he mostly stays well as long as he does his treatment on time. Last year, he had a major bleed into his coccyx where one of his friends (and I use that term loosely) kicked him. Well it must have been one hell of a kick because he was in hospital for two weeks and had to be operated on to drain a big haematoma on his coccyx. It was very nasty and also very painful. He had to move home

for a bit as well so the wound could get dressed each day by his nurse (his mother)…another stressful time his parents have weathered.

Max has been living away from home now for about 4 years. He handles his haemophilia very well. He prefers to be low key about his condition and tries to live a very full life. He has been overseas twice for extended periods of time. The first one was for 3 months when he was 19 and included a contiki tour. The second one was for longer, about 4 months and included many obscure places in Eastern Europe.

Organising the trips was difficult as Max had to take half his treatment product with him and then organize a pick up point for the second half. He had to take a portable fridge with him as the product has to be kept at a certain temperature. So looking for power points all the time was difficult as you can imagine and also lugging the fridge around. Half way through both trips he had to fly to St Marys hospital in London to pick up the factor VIII product which had been sent from Australia. He had to have lots of letters from doctors explaining his medical condition and what all the small bottles were and of course airport staff wanting to know what all the needles were for. But despite all the obstacles Max was determined he was not going to let his haemophilia stop him from travelling the world with his mates. He even did skydiving in Switzerland which fortunately his mother didn't know about until he got home. His father and I are so proud of him and his travels. He loves travelling and I'm sure a third trip is on the horizon.

Our daughter Emma was married in 2017 and is now considering her options of becoming a mother. She was tested for her carrier status when she got married and tested positive to being a carrier. This means she has a one in four chance of having a son with haemophilia. Emma has been to genetic counselling to see what her options are. She can take pot luck or she can follow the IVF path. However, the cost of the treatment is $10,000 and $6,000 for every attempt thereafter. Gene therapy trials are well under way with haemophilia. The outlook is very promising and hopefully in the not to distant future those with haemophilia will be treated with gene therapy to minimize their disorder.

The product that Max uses is very expensive. Unlike many developing countries the treatment is free in Australia so he is very lucky in that department. His treating hospital is the Alfred where they have a Haemophilia Treatment Centre which is world class, again very lucky and he regularly visits his haematologist who keeps a watchful eye on him.

Finally I would just like to say that Max has grown into a fine young man who has a very endearing personality and is loved by all who know him. He has never let haemophilia define him. To him it is just a small obstacle given to him in the journey of life. He certainly lives life to the full and has taken on many challenges that even those without haemophilia wouldn't consider. I wouldn't change anything about Max and I really think that haemophilia has made him the kind, considerate and gentle man that he is today. His father and I are so proud of him.

Bronwyn Grant
HFV Member

Bronwyn receiving an award for presenting a talk at Keilor Probus

*** Bronwyn and her husband Dean have been avid supporters of HFV for many years. They attended HFV Camps when their children were young and continue to support HFV through various fundraising they do for the Foundation throughout the year. We are very grateful to all our supporters, including Browyn and Dean, without whom we would not be able to fund our member programs and offer the opportunity for our community to Connect, Support & Empower.**

Sharing our journey with vWD

I was diagnosed with von Willebrand Disease (vWD) Type 1, in my early forties. My brother was going in for surgery and his doctor wanted him to be tested for any issues that might arise, this is when we first found out about vWD. It turns out our mother was the one who has vWD and has passed it down to me and my brother. My father had haemochromatosis and he passed that down to my other brother. I have two daughters and both have vWD as well.

When I was younger I had lots of nose bleeds, very heavy periods and always would bleed from small paper cuts. I have suffered with low iron all my life and have to take iron tablets as well as eat high iron foods.

I found out about HFV through the Alfred hospital. I attended a conference in Melbourne and became a committee member as I feel there's not enough information about vWD and I feel that we don't really get noticed or we get brushed off. I want to raise awareness about vWD to the wider community and help increase knowledge of vWD to health professionals.

I don't believe many doctors or nurses are informed about vWD or how to treat people with vWD. I've attended hospitals for surgery and the hospital would clear the day of patients as they didn't know if they would have an issue with me. The nurses would google my condition in front of me, so they knew what vWD was. I would hear them talking on how to mix DDAVP and they had no idea what not to do after having DDAVP.

We may be seen as a low risk group of 'bleeders' (although some with vWD have severe episodes) but we do not have enough support in our condition. vWD is the most common type of bleeding disorder however, we rarely hear about it. Some people with vWD may have few symptoms but there are others like myself and my girls who do have issues that affect our day to day lives. I have suffered throughout my life particularly with joint pains and so have my girls. I would love to know if anyone else who has vWD has any issues that they are curious about.

Robyn Heal
HFV Committee Member

My name is Cara and I was diagnosed with Von Willebrand Disease, Type 1, at around 12 years old. I was tested for vWD as a result of my uncle's diagnosis, on my mother's side. My uncle was tested because of a surgery and his doctor wanted to be thorough to ensure there weren't any complications. My mother and sister both have vWD, though they didn't have the same symptoms as me, they were also diagnosed when I was. Looking back I did have some of the symptoms, mainly nose bleeds, which I have had all through my childhood.

Having vWD has mainly affected the medical side of my life, and luckily hasn't affected my personal life too much, though it has been useful to know about, as I've had a surgery where I was able to have a treatment beforehand to control bleeding, as well as treatment in preparation for tattoos. I've found that not a lot of people are informed about vWD and that can be troublesome, like having to explain to some doctors what it is, and how to treat it. There are some great resources that I was given from my HTC that explained what vWD is, as well as some resources from HFV that also included other people's stories.

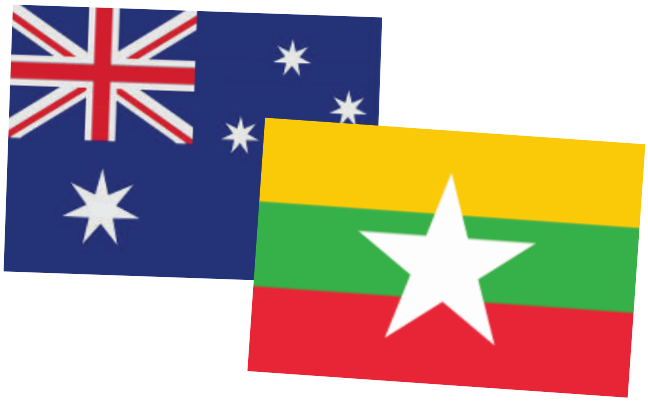
I learnt of HFV while attending a conference for Bleeding Disorders, where I met part of the committee, and other youth from Victoria, as well as others from across Australia. My mum and I decided to become members to be a part of a community with others who can help us understand our disorder, and connect with other people with bleeding disorders. I joined the committee to bring the perspective of a younger generation, which will always be important to help HFV appeal to their younger members. Through HFV I would like to connect with more people with vWD, I feel like people with vWD don't get involved as much as they should with HFV, and it would be a great opportunity to meet people with the same disorder as me, and share our stories with each other.

I would hope that there is more education provided to doctors about vWD, as it's not okay for a doctor at a hospital to be taught about a condition from their patient, and I would hope for more awareness and peer support groups, as I was never able to meet any other person with a bleeding disorder, until I found HFV. Having vWD has opened up new opportunities for me and it will be exciting to see where those opportunities will lead.

Cara Gannon
HFV Committee Member

Please contact the office if you have vWD and would like to connect with Robyn and Cara.

REFLECTIONS ON TWINNING WITH MYANMAR



Sam Duffield and Leonie Demos share their experiences of representing HFA at the National Member Organisation Twinning Meeting with the Myanmar Haemophilia Patient Association in March 2019. Below is an abridged version of an article that will feature in HFA's National Haemophilia September 2019 edition.

As a mother of a son with haemophilia it has always been a double-edged sword for me. On one side it feels unfair and unjust that we as a family have had to watch him with his challenges in life and the times that pain has been his enemy. However, like most of us I have always been so grateful for the medical care and the support we have in Australia. Challenges are shared with amazing medical professionals and treatments are of a quality that were nothing but dreams to those generations before us. From diagnostics which we take for granted, public transport that is affordable and available to get to hospital if we need to, to government-funded treatment product in Australia, we are confident we will have access to high quality health care every day. This was highlighted again for me during my twinning visit to Myanmar.

Our new friends in Myanmar share a genetic disorder like us. They share a heart and passion to work together to support each other and provide support for the rough times they face. But they have great challenges every day in living with a bleeding disorder and much to do to achieve the level of diagnostic, hospital services and treatment they need to live well.

It is an exciting opportunity to plan for a twinning with Myanmar. They have been making strides ahead both with their haemophilia services and with their Patient Association. Sam mentioned that a haemophilia treatment centre has now been opened in Yangon and that the haematologists have undertaken further training on haemophilia management after an HTC twinning with the UK. The Patient Association has been meeting to discuss planning for future directions with members from both Yangon and the second largest city in Mandalay. They have been working closely with hospital teams to broaden their reach and address isolation issues. They have also had successful events to raise awareness with the public.

Sam and I felt our privilege in every way during our time in Myanmar. We also felt the hope and passion of a group of very special people who want to work together to improve treatment, care and peer support in their country. We have skills and experience to share and together we will work to do what we can knowing all our extended community is behind us.

Watch this space as the twinning takes off and consider the ways you can also step out of our shared privilege and support a beautiful community in Myanmar.

Leonie Demos
HFV President

During our discussions we talked about how the Myanmar group and HFA volunteers might work together to strengthen their advocacy skills so they can represent their needs to other organisations and the government to continue to improve the situation for people with haemophilia.

As with any organisation including our own haemophilia foundations, it's all about having a strong governance structure and driven leaders, and Myanmar has some very smart driven young leaders, who are looking to do more to help their community.

But this is also a small reminder to the community out there reading this, to be involved whenever possible, because without your involvement, your foundation doesn't know how to help you. Be involved, because you are not alone, there might not be a lot of us, but we all share a lot of the same experiences and can help each other and continue to improve the situation locally within Australia and globally.

Sam Duffield
HFA Youth Leader

LADIES DAY 2019

Every year we like to offer a different activity for our Ladies Group. In the past we have enjoyed events like salsa dancing, learning circus skills and high tea on the Yarra.

This year it was agreed that a relaxing massage was just what was in order for our hard working ladies!

Twelve lucky ladies were pampered with either a neck and shoulder massage, a foot massage or a back massage. The beauty of the venue was that there was plenty of room for us to mingle and chat over a coffee and nibbles whilst waiting for our massage.

There was wonderful mix of ladies who joined us on the day. Those with bleeding disorders, mothers, grandmothers and siblings.

During lunch stories were shared of challenges and triumphs of life and we enjoyed being surrounded and supported by our peers.

Treating bleeds with ice

The RICE (Rest, Ice, Compression, Elevation) principle continues to be advised for bleeding episodes in patients with Haemophilia with ice being an integral component.

However, we recognise that ice is not helpful in certain situations for certain patients. Here we will discuss how ice works so it can be best understood when to use it. To do this, let's talk about how ice affects the body through the following mechanisms: vasoconstriction, reduced secondary damage and reduced pain.

Vasoconstriction

Vasoconstriction is a process where blood vessels narrow. When exposed to cold temperatures, this process kicks in and has the effect of reducing blood flow to the targeted area (think of the pale appearance of your fingers in cold weather).
This is beneficial since it reduces the amount of blood entering a joint or muscle during a bleed.

Reduced secondary damage

Bleeding results in secondary damage to tissue (particularly a joint). Ice can reduce this by limiting secondary inflammation (through vasoconstriction) and keeping the tissue around the bleed from being affected.

Pain

Ice has a 'numbing' effect on areas it is applied to. It does so by affecting the ability of nerves to send the signals from the tissue, thereby reducing the feeling of pain.

When Ice may not be helpful

Due to it's effects on blood flow (through vasoconstriction), ice can make an arthritic joint feel more stiff and uncomfortable by affecting the synovial fluid that lubricates a joint. If you are experiencing arthritic joint pain only, then it is perfectly fine to forego using ice if you feel it isn't helpful. However, if there are signs of bleeding such as increased swelling then ice is usually recommended. As always if in doubt, contact your Haemophilia Treatment Centre for advice.

Scott Russell

Haemophilia Physiotherapist
Royal Brisbane & Women's Hospital

Reprinted with permission from HFQ

REGIONAL & OUTER METRO VISITS

Epping

Cranbourne

We are delighted to say that HFV have had two successful visits to Cranbourne and Epping in our latest outreach program. A need to connect with more outer regional areas was identified by the Alfred treatment centre staff which has proved to be very rewarding.

Leonie, Dan and Adam (committee members) joined with over 20 other people affected by bleeding disorders at the Settlement Hotel in Cranbourne. There was a real mix of those well connected with HFV and first timers. There were people with vWD, haemophilia, parents and siblings. For our committee, it was important to get a deeper understanding of the individual and family impact a bleeding disorder can have. Speaking to different people about their own experiences is often the best way to identify issues where HFV can assist. Hearing from those who have not connected previously is also so beneficial to understanding where we are missing opportunities to connect.

In July, myself, Andrea and Leonie headed to Epping. It was another great opportunity to connect with our community. We had a newly diagnosed family, as well as a number of others that have been connected with HFV for a number of years.
It is so valuable for us as staff and committee to attend these events as we gain such an insight into the challenges people face day to day with their bleeding disorder.

It is very clear that for parents of children with haemophilia the journey is life long. Their care and support of their children continues well into adulthood. Concerns for their children do not diminish once they become adults so it is very important that parents and siblings alike have an opportunity to share the impact they feel as a care giver. Many siblings feel a huge responsibility over the welfare of their sibling with a bleeding disorder. This has not been imposed by their parents, it is often a natural outcome of a caring family dynamic. Those siblings need a voice and platform. Young families can often be impacted greatly, not only by the shock of a new diagnosis but also grappling with the care of their child. Often grandparents can step in and assist but sometimes families are isolated and this adds to the burden, often meaning parents working alternate shifts so that someone is there to look after their child. HFV can't replace family support but we can ease the burden of isolation that many people face. Through connecting and supporting each other the impact and burden of bleeding disorders can be lessened.

Thanks to both HTC's for their support in mailing invitations to patients in those areas. Without their support we wouldn't have had the opportunity to connect with new families and continue our work of CONNECT, SUPPORT & EMPOWER.

I'm a bit confused by the Disability Support Pension (DSP) which I get, National Disability Insurance Scheme (NDIS) & MyAged Care. Does one affect the other? I live with my mum who is getting older and slower every day and we are both beginning to have problems and might need help.

Disability Support Pension

The pension (Disability Support Pension) is your income, that is means tested and based on your inability to work full-time or part-time. It does allow you to work part-time/casually up to a certain level of gross pay (pre-tax amount). You must report any gross pay & the number of hours fortnightly to Centrelink, and then they will deduct amounts accordingly.
This does not affect the NDIS.

Please note your local Centrelink office should have a social worker available to clarify any questions if you still feel confused by the front counter staff. Make an appointment to sit down and raise your questions or concerns about your entitlements or your application. This can include an appeal against the decision to refuse your application.

NDIS

The NDIS is about your need for services, support and equipment/ modifications to the home/car etc which will enable you to be as independent as possible. Having haemophilia as a medical condition in itself will not suffice but it is about the impairments associated with haemophilia that impact on your day to day functioning, and capacity to be independent that must be impressed upon in your Access Request form.
You need to identify your needs, have a physiotherapist/occupational therapist/medical officer assessment to support your request.

To get started you must call the NDIS to request an Access Request form to be sent to you, complete this form in consultation with your GP initially or your specialist.
As an applicant you must be under 65 years of age.
If you are successful in accessing the NDIS and you later turn 65, you should still be able to have NDIS support.

MyAged Care

MyAged Care is a referral and information system for anyone 65 years and older. This is NOT the age pension available from Centrelink.
This is where you or your family go to begin the process of seeking appropriate services. Equipment, specialist aged care assessments of needs that assist in keeping you or your ageing family member at home and independent for as long as possible. It is also the point at which you can request an in home assessment for possible hostel/ nursing home placement and access to planned respite stay for the ageing person.
You can still seek out your family GP on accessing the MyAged Care as well. It is important once you register here, you keep the reference number you receive handy at all times to make further enquiries.

MyGov

MyGov portal is the online service that allows you to interact with Centrelink, the ATO, Medicare, and may link your other public services including your NDIS account.
It is almost mandatory if you want to interact with Centrelink.
You will need to create a MyGov account with a reference number and password and keep these details handy when ever making inquiries.

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

HANDY LINKS:
Centrelink
https://www.centrelink.gov.au
ph. 13 23 00

https://www.ndis.gov.au/applying-access-ndis/am-i-eligible
Ph 1800 800 110

https://www.myagedcare.gov.au/ ph 1800 200 422

MyGov https://my.gov.au/
ph. 13 23 07

Challenging the STATUS QUO

The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders will be held at the Novotel Manly, Sydney, 10-12 October 2019.

Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

PROGRAM
Chaired by Dr Liane Khoo, Director, Royal Prince Alfred Hospital in Sydney, NSW, the program committee is developing a multidisciplinary program which will interest everyone.

KEYNOTE SPEAKERS
International expert on pharmacokinetics (PK) and measuring treatment outcomes in haemophilia, Prof Alfonso Iorio from the Department of Health Research Methods at McMaster University in Canada, will be presenting on his work and contributing to the discussion about where treatments are going in Australia. We will also have a plenary session with Dr Tim Sharp, AKA Dr Happy. Dr Sharp is an expert in human behaviour, in what makes people tick; but his focus is mostly on the promotion of positive psychology principles. His passion lies in helping individuals, teams and organisations to really thrive and flourish.

SHOULD I ATTEND?
The Conference is a great opportunity for the bleeding disorders community and people working in the sector to hear the latest information and discuss current and emerging issues together. It is a niche conference, focused on the specific questions relevant to bleeding disorders, and caters for all delegates. We invite the following people to attend:
• People with haemophilia, von Willebrand disease or other bleeding disorders and their families - parents, siblings, partners – all ages welcome from young adults to seniors!
• Health professionals – doctors, nurses, physiotherapists, psychosocial workers and other health care providers
• Treatment product producers, suppliers and service providers
• Policy makers and government officials
• Haemophilia Foundation volunteers and staff.

COMMUNITY FUNDING
HFA has allocated funding to assist people living with a bleeding disorder, relatives/partners or carers to attend the Conference for expenses such as flight, registration, accommodation. Part funding applications are encouraged so we increase access and you will generally be expected to contribute towards your costs. Applications will be assessed on their merit – it is in your interests to provide full responses to the questions on the application form. There is also still some funding available to assist HFV members to attend the conference. HFV may subsidise the cost of registration and accommodation. Please contact HFV ASAP if you require assistance or go to: www.hfv.org.au/get-involved/news/2019-australian-bleeding-disorders-conference-1

MORE INFORMATION AND DETAILS
• Visit www.haemophilia.org.au/conferences and download the registration and information brochure or
• Email hfaust@haemophilia.org.au

HFV LIFE MEMBERSHIP

CALL FOR NOMINATIONS

HFV Life Membership nominations are open to people who have made an outstanding contribution to the work of HFV, usually members or past members of the HFV Committee. This may include the work of **medical personnel, volunteers and other individuals** who have made a significant contribution to HFV over many years.

Please email nominations to the HFV info@hfv.org.au (or phone on 9555 7595) by 4pm Thursday 17th October 2019

LONELINESS

a new public health challenge emerges

Loneliness is proving to be more than just part of the human condition. New research shows it's a serious public health problem, for young people as much as the elderly.

The evidence is startling. Feeling lonely can pose a bigger risk for premature death than smoking or obesity, according to research by Julianne Holt-Lunstad, Professor of Psychology and Neuroscience at Brigham Young University in Utah, USA.

Links to depression may not be surprising, but the idea that loneliness can be associated with poorer cardiovascular health and, in old age, a faster rate of cognitive decline and dementia is repositioning loneliness as a public health issue.

'There is robust evidence that social isolation and loneliness significantly increase risk for premature mortality, and the magnitude of the risk exceeds that of many leading health indicators,' Holt-Lunstad told the 125th Annual Convention of the American Psychological Association in August 2017, adding, 'Many nations around the world now suggest we are facing a 'loneliness epidemic'. The challenge we face is what can be done about it.'

Holt-Lunstad drew on data from two meta-analyses for her presentation. The first found greater social connection conferred a 50 per cent reduced risk of early death. The second examined 70 studies and concluded that social isolation, loneliness or living alone posed risks for premature death that were as big as or bigger than obesity, smoking (less than 15 cigarettes a day) and air pollution.

PINPOINTING THE CAUSES

'We know that the impacts of feeling lonely and isolated impede your health, whether that's your mental health or physical health,' says Irene Verins, Manager, Mental Wellbeing at VicHealth. 'We need to identify the factors that influence loneliness – at the level of the individual, the local community and wider society – to get some idea, or a clue, as to where to look for solutions. New research is required that tells us about levels and experiences of loneliness in Australia.

'We also know that loneliness impacts more on those people who are the most vulnerable. We need to look at how we could approach the issue of loneliness for the most disadvantaged in the community first.'

Loneliness can affect people at any point, but is more common among two key groups: older individuals aged 75 and above and, perhaps surprisingly, young people aged 15–25.

Figures released in April 2018 by the UK's Office for National Statistics showed individuals aged 16–24 reported feeling lonely more often than people in older age groups. The statistics also identified a particular risk of loneliness among young people who were renting and who did not feel a sense of belonging to the local area.

Although research in Australia is currently limited, a 2015 survey funded by VicHealth found one in eight young people aged 16–25 reported a very high intensity of loneliness.

Loneliness is commonly understood as an emotional response to the perceived mismatch between the amount of personal contact a person wants and the amount they have. In the UK, the Campaign to End Loneliness intensifies the focus to identify two types of loneliness: individual and social.

Individual loneliness occurs when a person is missing someone special such as a partner or close friend with whom they had a close, emotional bond.

Social loneliness refers to the absence of a social network made up of a wide group of friends, neighbours and colleagues.

The quality of those social connections is also important. Relationships need to be reciprocal, with those involved both sharing a sense of happiness, satisfaction and self-worth. (In 2012, a team at the University of California published the results of a study that found significant numbers of older people who identified as lonely were either married or lived with others.)

WHAT COULD SOLUTIONS LOOK LIKE?

As loneliness and social isolation can arise from very different factors, interventions to alleviate them will also be varied. They could include projects that support connections, such as online groups, volunteering programs and befriending projects, and other

approaches such as local neighbourhood approaches. Interventions can be aimed at the individual, community or societal level.

'The most effective way to reduce loneliness is to make people feel connected to their community,' says Verins. 'Those communities may not be geographic – for example, they may be online for LGBTI youth or rural young people – but what's important is they share common interests and develop meaningful connections.'

Holt-Lunstad suggests interventions ranging from a bigger focus on social skills training in schools, to making social connectedness checks part of standard medical screenings. Human Resources departments could prepare workers for retirement socially as well as financially, she says.

Planning out suburbs so they are walkable and include social spaces where people can meet up, such as gardens or recreation centres, is also crucial. Media campaigns could raise awareness about loneliness while also removing some of the label's stigma.

Public Health England, in its 2015 Reducing social isolation across the lifecourse report, highlighted that 'access to transport is also vitally important for building and maintaining social connections'.

EVIDENCE-BASED CAMPAIGNS

Experts emphasise that any interventions to reduce loneliness and social isolation should be evidence-based. The Campaign to End Loneliness in the UK, which launched in 2011, began by building a research base and connecting different groups interested in reducing loneliness so they could learn from each other. It then partnered with health and community organisations to scale up successful initiatives.

Its first public campaign about loneliness was in 2017, and during this year it will launch the Be More Us movement to promote social connectedness right across the country and generations.

'British people are famously awkward and a bit stiff upper lip, so our new movement is about breaking down those barriers and finding what we have in common,' says Alice Stride, the Campaign to End Loneliness's Media Communications Manager.

'Intergenerational friendships and intergenerational connections are going to be a really important part of everybody's solution to loneliness, not just for older people but for younger people, too.'

Online tools are also showing their worth. Australian initiative Gather My Crew is a free, online rostering tool that helps family, friends and community members to organise themselves in support of someone who needs help. Rostered tasks can include practical help, like lending a hand to someone who is in poor health by picking up their kids from school or doing their supermarket shopping. But they can also include social visits or phone calls to a friend, family member or neighbour at risk of social isolation.

Another Australian online initiative is the Moderated Online Social Therapy program (MOST) from Orygen. MOST is proving useful for vulnerable young people experiencing mood disorders, anxiety and psychosis.

'It's sort of like Facebook but we also build in online therapy with clinicians and peer workers,' says Dr Simon Rice, a clinical psychologist and Research Fellow at Orygen. 'Young people, who sometimes are quite socially isolated and lonely, get a huge benefit from that online connection with other people in a safe, supported environment. That can be quite restorative to their sense of self and their confidence in their functioning as well.

'We encourage young people to use the skills and confidence they're learning in the online environment and use them offline. We want those skills to translate.'

TAKING A POSITIVE APPROACH

Dr Michelle Lim leads the Social Connectedness Laboratory at Melbourne's Swinburne University of Technology. Her six-week Positive Connect study used strengths-based group therapy to assist young people experiencing psychosis and social anxiety build their social interaction skills. The study had just a 10 per cent dropout rate from participants, compared to the usual 50 per cent.

'Often psychologists are overly focused on deficits and risk,' Lim explains. 'In our traditional method in health services, we often go, 'Hey, so what's wrong with you today? How depressed are you? Are you feeling suicidal?' And we forget to ask what's right with you.

'In the Positive Connect study, we never once mentioned the word lonely, and we never once mentioned the word psychosis. It was very much about let's not focus on deficits and illness, let's focus on strengths and be about building healthy social connections, to reconnect with people and change acquaintances into friends.'

A well-known community initiative that tackles social isolation is the Australian Men's Shed Association. Its CEO David Helmers says, with a little humour, 'There are currently 130-odd more Men's Sheds [987 Sheds] in Australia than there are McDonald's restaurants. Not that it's a race.'

The Sheds target men who are no longer in paid employment, through retirement, redundancy or other reasons. Men can come to the Shed to build and repair items for the community, but that's not the place's main purpose.

'The most important thing is the men getting together, building those relationships, that brotherhood that exists in the Sheds. They're finding new friendships but, most importantly, finding meaningful purpose,' says Helmers.

COUNTING THE BENEFITS

With the health burdens of loneliness and consequent impact on health services now well identified, it makes

sense to put money into interventions that deliver the most benefit. It would be easy to say a smile or peal of laughter are priceless, but government funding demands more rigour.

Last year, researchers from the London School of Economics prepared a brief for the Campaign to End Loneliness and determined that every £1 spent on a successful loneliness intervention in the UK delivered a £2-£3 saving in costs for the community.

They also identified three broad approaches that were being used to measure the value of interventions: conventional cost effectiveness analyses, return on the investment to the public purse, and social return on investment (SROI).

The SROI methodology starts with a discussion with stakeholders on why and how they believe an action will work; they then proceed to estimate the size of the effects and place a monetary value on them. Many of these monetary benefits do not relate to changes in use of public services and resources but are more subjective concepts, such as the value of developing new friendships.

'We need to think about social return on investment in addressing loneliness, and that's related to how the loneliness of individuals impacts the social cohesion of the community in general,' says Verins.

'If you have a bunch of people who are disconnected and isolated, it's negative for the community. The cost both in terms of their poor health outcomes and the lost contributions they could have made to their community will be expensive; and higher than if you'd connected them in the first place and diminished their level of loneliness completely. We know that participating in your community is beneficial for individuals and our society.'

PREPARING FOR WHAT'S AHEAD

So is Australia ready to deal with an epidemic of loneliness? Not yet. Compared to the UK, we are only just starting to undertake the sort of research needed to help deliver targeted, successful interventions.

'We really don't have good Australian studies, and that's what we're trying to do right now – build the evidence about what actually drives loneliness in Australia,' says Lim, who advises the Australian Coalition to End Loneliness.

Later this year, VicHealth will release Women, Their Social Connections and Social Cohesion, a report that represents one of the first comprehensive reviews of how women connect in Australia.

Associate Professor Nicola Reavley, and Dr Georgina Sutherland, at the University of Melbourne's Centre for Mental Health, analysed studies and interviewed young mothers, migrant women and older women.

'It's interesting that with older women, most of the studies found that there was not really any decline in social networks over time. In fact, both separation and widowhood were associated with increased social network time for women,' Sutherland says.

'The only group of women this finding didn't hold for was older women who were not born in Australia. They had broad social networks to start with, but that decreased with age, though not necessarily with those life transitions.'

Such insights help fill in a small piece of the loneliness puzzle, but it's obvious more research is needed. With social isolation being a bigger risk to health than obesity, there really is no time to waste.

© Victorian Health Promotion Foundation (VicHealth).

Source material available at www.vichealth.vic.gov.au

CALL FOR NEW HFV TREASURER

After many years supporting HFV as treasurer Zev Fishman has decided to step down from the role at the next AGM. We are looking for a suitable candidate to fill the position. Zev has shared some valuable insights here.

I have been the HFV treasurer for 6 years and will be stepping down from the role at the next AGM.

It has been a valuable experience being in this role and an absolute pleasure being on the HFV committee. I have made many great connections and friendships over the years.

I would dearly love to recruit a new treasurer from our own community to enrich our passionate team. We are looking for someone with a business, accounting and finance background. This role also oversees HFV's strategic financial management.

I leave the committee knowing we are in a very positive position both financially and from a governance perspective. Anyone interested in the position is welcome to attend our next committee meeting as an observer. Please contact me directly on 0419 552695 if you would like to chat about the role or contact the office staff on 9555 7595.

Zev Fishman

NEWS FROM THE ROYAL CHILDREN'S HOSPITAL

The Haemophilia Treatment Clinic at the Royal Children's Hospital is pleased to announce that Dr Sally Campbell has been appointed as a consultant haematologist and will be seeing patients with Dr Chris Barnes in the haemophilia clinic. Sally is known to many of you having worked at the Children's Hospital for a number of years initially as a registrar and then as a fellow with Department of Haematology.
Sally already has significant experience in the management of patients with bleeding disorders and we are very lucky to have her working with the clinical team.

GETTING OLDER PROJECT UPDATE

Where to from here?

Preetha Jayaram, HFA Getting Older Project Officer

Special thanks to all the community members and haemophilia health professionals who have welcomed me since I took up the position of Getting Older Project Officer at HFA and for your participation in the project interviews and community forums. There has been much enthusiasm and support to explore current and emerging issues and how to 'future proof' as people grow older.

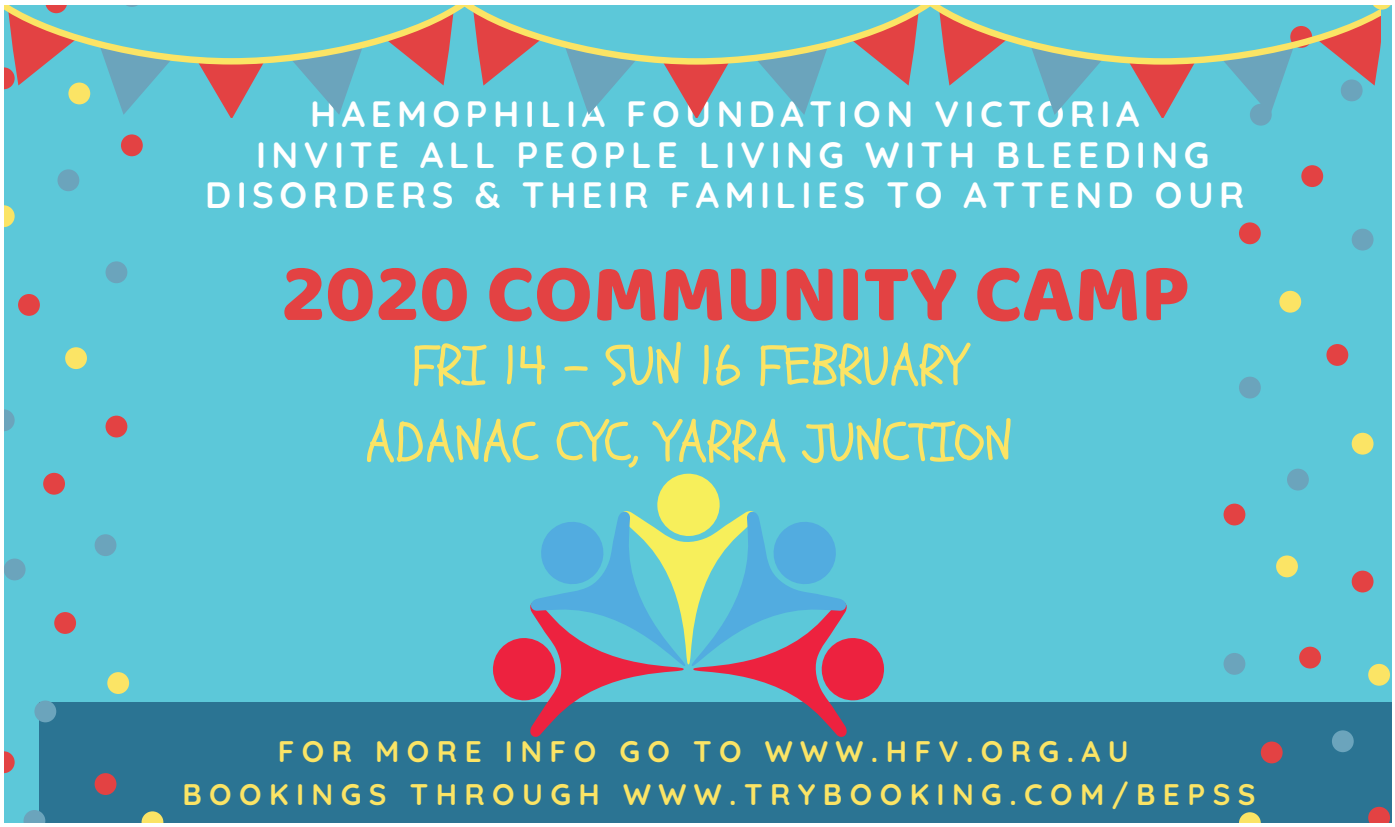
COMMUNITY SURVEY

The next step is a HFA survey to hear from the wider bleeding disorders community. The survey aims to identify the range of needs people with bleeding disorders and their partner/family or friends/carers may have as they get older. It asks questions about work/retirement, housing and insurance, aspirations for the future, information and education, computer use, support, and social connectedness.

If you want to take part, you will be able to do the survey online or in print. Please check your mailbox in the coming months and if you know anyone else who might be able to complete the survey, please tell them about this. Let us know what your concerns around getting older and what would help now and in the future!

Any questions?

Contact Preetha Jayaram at HFA.
Ph: 03 9885 7800
Tollfree: 1800 807 173
PJayaram@haemophilia.org.au



A NO HEP FUTURE

The World Hepatitis Alliance has committed to eliminating viral hepatitis by 2030. Imagine a future without hepatitis C. Can we achieve this in the Australian bleeding disorders community?

WHY MISS OUT ON A HEP C CURE?

New revolutionary hepatitis C treatments are widely available in Australia.

- Very high cure rates
- Tablets not injections
- Few if any side effects.

HAVE YOU BEEN CURED OF HEP C?

Are we on the way to eliminating hepatitis C in the Australian bleeding disorders community? Haemophilia Treatment Centres are currently collecting data to find out which of their patients have been cured of their hep C and their current liver health. You can help this work by making sure your HTC has your results for:

your hepatitis C treatment

- your latest HCV PCR test
- your most recent liver health test/fibroscan.

Ask your hepatitis specialist or GP if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need to have liver health checks regularly.

DO YOU HAVE HEPATITIS C?

Many Australians with bleeding disorders and hep C have had treatment and been cured – but some may not even know they have hep C.

YOU COULD BE AT RISK

- If you ever had a blood product for treatment before 1993 – even as a baby
- Or if you have shared equipment that could allow blood from an infected person to get into your blood stream, eg injecting equipment, non-sterile tattooing, medical care overseas
- Still wondering? Take the Hepatitis Risk Quiz to see if you are at risk - http://www.worldhepatitisday.org.au/quiz
- Is this you or someone you know? Have you ever been tested for hep C? If not, now is the time to be tested - and have treatment to be cured, if you do have hep C!

DON'T PUT IT OFF!

Is life too busy to get hep C testing and treatment? Are you sick of clinics and appointments? Get hep C off your list!

Talk to your doctor about quick and easy solutions. Get cured today!

Is it too hard to get to a hepatitis clinic? Talk to your local doctor and see what arrangements can be made to have your tests and treatments locally. Show your doctor the GP Fact Sheet on hepatitis C and bleeding disorders.

WHAT ELSE CAN YOU DO?

Spread the message - if you know someone who might have hep C and doesn't know, or hasn't taken up treatment yet, let them know about the new treatments.

As a Partner in the national World Hepatitis Day Campaign, HFA works with Hepatitis Australia and State and Territory Foundations on the annual national awareness campaign and is committed to making a difference on hepatitis C in Australia.

https://www.haemophilia.org.au/about-bleeding-disorders/hepatitis-c/world-hepatitis-day-2019

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

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.

HAEMOPHILIA FOUNDATION VICTORIA

AGM & CHRISTMAS PICNIC

PLEASE JOIN US FOR OUR ANNUAL AGM & PICNIC AND ENJOY A DAY OUT WITH OUR COMMUNITY!
BYO PICNIC. HFV COVERS ADMISSION

10.30AM - 2.30PM
SUNDAY 17TH NOVEMBER
REPTILE LAWN 9, MELBOURNE ZOO

BOOKING ESSENTIAL
WWW.TRYBOOKING.COM/BEPMF

HAEMOPHILIA FOUNDATION VICTORIA INC
13 Keith Street
Hampton East VIC 3195
Phone: 03 9555 7595
Fax: 03 9555 7375
info@hfv.org.au
www.hfv.org.au

PATRON
Dr Alison Street AO

EXECUTIVE ASSISTANT
Andrea McColl **andrea@hfv.org.au**

COMMUNICATIONS COORDINATOR
Julia Broadbent **julia@hfv.org.au**

COMMITTEE OF MANAGEMENT:

PRESIDENT **Leonie Demos**
VICE PRESIDENT **Sharron Inglis**
TREASURER **Zev Fishman**
EXECUTIVE MEMBER **Dan Korn**

GENERAL COMMITTEE:
Karen Donaldson
Donna Field
Cara Gannon
Robyn Heal
Erika Mudie
Adam Zulawnik

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

SUBSCRIPTION RENEWAL **REMINDER** 2019/2020

If you have not yet paid your membership please do so ASAP!

renew online @ www.hfv.org.au/get-involved/memberships

VICTORIAN HAEMOPHILIA CENTRES

Henry Ekert Haemophilia Treatment Centre

Royal Children's Hospital
Flemington Road, Parkville
P. (03) 9345 5099 E. he.htc@rch.org.au

Dr Chris Barnes	Director Henry Ekert HTC
Dr Sally Campbell	Consultant Haematologist
Janine Furmedge	Clinical Nurse Consultant
Julia Ekert	Office Data & Product Manager
Nicola Hamilton	Physiotherapist
Wade Wright	Social Worker

Ronald Sawers Haemophilia Treatment Centre

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

Dr Huyen Tran	Director of RSHC
Penny McCarthy	Clinical Nurse Consultant
Megan Walsh	Clinical Nurse Consultant
Kara Cordiner	Haemophilia Nurse Consultant
Susan Findlay	Secretary
Alex Coombs	Haemophilia Social Worker
Jane Portnoy	Hepatitis C & Haemophilia Social Worker
Abi Polus	Physiotherapist
Frankie Mullen	Physiotherapist
Diana Harte	Psychologist
Debra Belleli	Data Manager

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 Fax: (03) 9555 7375
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.

REDCLASSIC

Supporting the Bleeding Disorders Community

WALK FOR BLEEDING DISORDERS AWARENESS

Bring your family and friends and join the extended HFV community for a LAP OF ALBERT PARK LAKE followed by a sausage sizzle

HELP SPREAD AWARENESS & RAISE FUNDS FOR HFV

2.00PM SUNDAY

20TH OCTOBER 2019

MORE DETAILS PLEASE GO TO WWW.HFV.ORG.AU
BOOKINGS ESSENTIAL THROUGH
WWW.TRYBOOKING.COM/BCQSH

HFV is excited to announce that our Walk for Bleeding Disorders will now be part of the national initiative RED CLASSIC. This gives us an opportunity to be part of the national awareness campaign, increased promotional opportunities and the flexibility to run, walk, ride, scoot in the future!